



ADDIS ABABA UNIVERSITY
COLLEGE OF LAW AND GOVERNANCE STUDIES
CENTRE FOR HUMAN RIGHTS

**IMPLEMENTATION OF SELECTED RIGHTS OF CHILDREN WITH
INTELLECTUAL DISABILITY IN AMBO CITY: ANALYSIS OF THE PRACTICE
AND THE LAW**

BY: METI ATOMSA

September, 2018

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**A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIRMENT FOR
THE DEGREE OF MASTERS IN HUMAN RIGHTS,**

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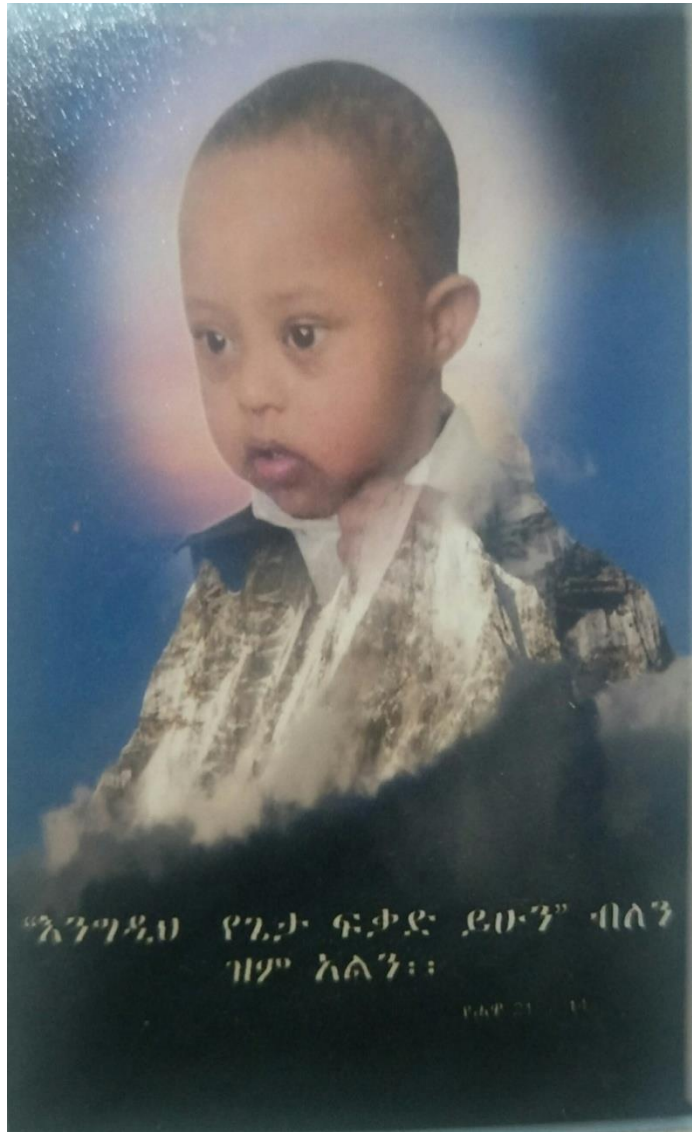
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Author

MetiAtomsa



YomiyuHachalu

*This work is dedicated to my sweet late nephew, **YomiyuHachalu**, who was with Down syndrome and only 3.*

Acronym

AAIDD: - American Association for Intellectual and Developmental Disability.

AAMR: - American Association on Mental Retardation.

ACRWC: -African Charter on the Rights and Welfare of the Child.

Art: - Article.

AU: - African Unity.

CRC: - Convention on the Rights of the Child.

CSA: - Central Statistic Agency.

Doc. Document

Dr. Doctor

E.C. Ethiopian Calendar

ECCL: - European Coalition and Community Living

ECOSOC: - United Nation Economic and Social Council

FDRE: - Federal Democratic Republic of Ethiopia.

GTP: - Growth and Development Plan

ICCPR: - International Covenant on Civil and Political Rights.

ICESCR: - International Covenant on Economic, Social and Cultural Rights.

ID: - Intellectual Disability

ILO: - International Labor Organization.

IMF: - International Monetary Fund.

IQ: - Intelligence Quotient.

MDGs: - Millennium Development Goals.

NGO: - Non-Governmental Organization.

NPA: - National Plan of Action.

Para. Paragraph

UDHR: - Universal Declaration of Human Rights.

UN: - United Nation.

OHCHR: - Office of High Commissioner for Human Rights

UN-DESA: - United Nations Department of Economic and Social Affairs

UNDP: - United Nations Development Program.

UNESCO: United Nations Educational, Scientific and Cultural Organization.

UNICEF: - United Nation Children's Fund.

US: - United States.

VCBRA: - Vision Community Based Rehabilitation Association

Vol. Volume

WFC: - World Fit for Children.

WHO: - World Health Organization.

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Abstract

This research is conducted with the main aim of assessing the implementation of some rights of children with intellectual disability. These are rights to family life, social inclusion, education, participation in play, recreation, and leisure, the best possible health, an adequate standard of living/ protection from poverty, and protection from all forms of violence and abuse in Ambo City. It is a qualitative research where interviews and field observations are applied as tools of data collection. The interview was a semi-standardized, where the interviewer was not limited to the questions listed under the interview guideline prepared; and the observation process was non-participatory. Both primary and secondary sources of data are considered within this research. Yet, it is a case study where 10 families having a child with ID and who lives in Ambo city participated in an in-depth interview.

The research finds that none of the above listed rights are being implemented as they should. Those children have an isolated life. They are only living with their family physically; are excluded from the community and not learning, at the time of data collection. Furthermore they are living under poverty, especially some of them lives under an extreme poverty. Violence and abuses are a problem that all of the informant children with ID faces. The failure of the government in its duties to respect, protect and fulfill, the negative attitude of the community including that of the families of the child, and also the extreme poverty account for the violations of these rights. Hence, issues of rights of children with ID are issues that need an immediate attention of all.

Key Words

Children with Intellectual Disability, Intellectual Disability, The right to family life, The right to social inclusion, The right to education, The right to participate in play, recreation, leisure and sport, The right to the best possible health, The right to an adequate standard of living/protection from poverty, The right to protection from all forms of violence and abuse, Implementation/execution

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Chapter One: Introduction

1.1 Background

Intellectual Disability (ID), once called mental retardation, is characterized by below average intelligence or mental ability and lack of skills necessary for day-to-day living. People with ID can and do learn new skills, but they learn them more slowly. There are varying degrees of intellectual disability, from mild to profound.¹

Someone with ID has limitation in two areas. *Intellectual functioning (IQ)* which refers to a person's ability to learn, reason, make decisions, and solve problems, and *adaptive behaviors* which refer to skills necessary for day-to-day life such as being able to communicate effectively interact with others, and take care oneself. Common causes are genetic condition (Down syndrome and fragile x syndrome), problems during pregnancy, child birth, illness or injury and unknown reasons in most cases.²

As a human being, children with ID are also entitled with all rights including civil, political, economic, social and cultural rights, exercised by all other human beings. However, because of their disability and vulnerability to various kinds of violations there is a need to give a special focus and address issues of children with ID. Convention on the Right of the Child and Specifically Convention on the Rights of Persons with Disability are international documents that address violations of rights against children with ID.

Ambo is a city found in West Shoa Zone of Oromia Regional State in Ethiopia. Of all 26,993,933 people in the region 282,544 live with different types of disability.³ According to the report of Vision Community Based Rehabilitation Association /VCBRA/, a non-governmental organization known for supporting children with disability in Ambo city, knowing the exact number of children with ID is difficult because of the existing attitude of the community. According to the report, there is yet such an attitude of hiding children with ID while the social workers conduct survey. However, currently the association gives an aid for about 20 children with ID.

¹See <https://www.psychiatry.org>, what is Intellectual Disability?, accessed on 23/10/2018

² Ibid

³ See Central Statistical Agency census report- 2007, p-312

1.2 Problem Statement

In almost all developing countries children with ID are traditionally considered as the sign of Gods' punishment for their parents' bad deeds, and were treated less of humans. They are segregated from all formal sectors of life including community, education and health since they are deemed to be worthless.⁴

Currently the attitude of parents living in developing countries and having a child with ID differs based on their exposure to formal education and modernization. While most of rural and illiterate families consider their child with ID as a curse and mistreat them, parents living in urban areas and with some degree of formal education are over protective.⁵ The former resulted to hiding, discriminating and hating the child. There are even extreme situations where the husband decides to leave his wife for the mere fact of giving birth to a child with ID. These worsen the problems encountered by the child since s/he will only be raised by a single mother.⁶ According to VCBRA, most of these parents are not even willing to show their child with disability to visitors. They rather confine them in a dark and isolated room, and goes to the extent of tying if they feel that the child is becoming violent.⁷

On the other hand over protective parents confine their child with ID in a given space in order to avert the possible danger that will happen unto him/her⁸ and they treat that child differently than the rest of their children, in a way that hurts the psychology of the child. Both attitudes of the parents are big barriers on the implementation of the rights of children with ID⁹

The problems above are in need of immediate attention, but there are also other problems that hinder children with ID from exercising their rights. These include the way they are perceived by the community at large, the impact of the level of official awareness special needs on the very concept of ID, the lack of commitment of government officials have towards realizing the rights of children with ID, and above all the mental disability of the child depriving of them of their right to speak unlike others. Taking disabilities related with mobility or sight, for instance

⁴HiwotAbebe, *The right to education of children with intellectual disability and its implementation in Addis Abeba*, Addis Abeba University School of graduate studies, Faculty of Law, March, 2011, p-3

⁵Ibid

⁶ Interview with V1, a supervisor at Vision Community Based Rehabilitation Association, at VCBRA office on 18/04/2018

⁷ ibid

⁸ Supra note 4

⁹ibid

persons with such disabilities have a sharp mind and in most cases stand for their rights. However, when it comes to ID, persons with this kind of disability depending on the degree of severity can hardly understand what rights are after all, let alone claiming for their rights. Hence, they need someone who speaks for them. Even more this children in most cases also have impairments related with hearing and talking.

According to the UN estimation, 3% of a given population is with ID.¹⁰ Thus, of 26,993,933¹¹ population in Oromia region, according to the 2007 national census report, 809,817.99 people are presumed to be with ID. However as per the report, only 15,726 were with mental retardation or with learning difficulty¹², using the words of the report which is to mean persons with ID. This counts 0.06% of the whole population. This shows a big disparity between the estimation and the report. Surprisingly the report shows the existence of only 2 persons with such disability in Ambo town.¹³ From this, one can understand how parents are ashamed of disclosing the existence of a child with ID in their family. Because, the time the survey is conducted there was one school called Ambo elementary school that has a special classes for students with special need which also includes students with ID and obviously it was not there for those two persons. The data shows under reporting. Hence, such and the like problems necessitated the research.

1.3 Research question

The main research questions that the research will try to address are;

- ❖ What are the specific rights for children with ID apart from the general human rights belonging to everybody?
- ❖ How are the rights to family life, social inclusion, education, participation in play, recreation, and leisure, the best possible health, an adequate standard of living/protection from poverty, and protection from all forms of violence and abuse in Ambo city being implemented?
- ❖ Are there any violations of such rights? If there is any, what accounts for the violations?

¹⁰ ibid

¹¹ See central statistical Agency census report- 2007, p-312

¹² ibid, p-333

¹³ ibid, p-390

- ❖ Who is responsible for the violation of those rights and how can the violations be averted or at least be minimized?

1.4 Objective of the Study

Assessing the extent of implementation of rights to family life, social inclusion, education, participate in play, recreation, and leisure, the best possible health, an adequate standard of living/protection from poverty, and protection from all forms of violence and abuse of children with ID in Ambo city is the main objective. The research will also have specific objectives.

These are:

- ❖ To explore the meanings and types of ID
- ❖ To describe what special rights of children with ID are nationally, regionally and internationally recognized,
- ❖ To assess the implementations of the rights
- ❖ To explain how and why these rights are violated,
- ❖ To identify bodies responsible for the violations of such rights,
- ❖ To pinpoint a specific focus area that needs a special attention on the case at hand
- ❖ To provide a picture of the practice and the law, so that possible recommendations are forwarded to fill the gap.

1.5 Scope of the study

To make the work manageable, the scope of the research will be limited to assessing the implementation of rights of children with ID in Ambo City. In this research a child means a minor who is under the age of 18 in accordance with the definition under the CRC and ACRWC.

After conducting an exploratory investigation on the case, the researcher reaches up on a conclusion that the *rights to family life, social inclusion, education, participate in play, recreation, and leisure, the best possible health, an adequate standard of living/protection from poverty, and protection from all forms of violence and abuse* are rights of children with ID that are being highly violated. The exploratory investigation is conducted by the researcher before deciding to work on this topic. It was first conducted by review of literature to know the status of children with ID throughout the world. Secondly the researcher went to Ambo city to figure out

whether children with ID who lives in the city are facing problems related with human rights and if so, on what specific rights they are facing problems frequently. VCBRA helped the researcher on this issue and the researcher selected the above listed rights as rights that need an immediate attention and reaction. Moreover, these rights are selected since they are attached to the day today living of the child with ID.

Hence, though children with ID also have other rights that might possibly be violated, since the above listed rights are found to be rights that are frequently being violated and are rights related with the day to day life of the child with ID, the research is conducted on the bases of special focus of these rights.

Geographically, the practical part of the research will be undertaken only on Ambo city.

1.6 Significance of the Study

The issue of children with ID these days is among issues with lower attention by all. The research will particularly focus on the violations of some selected rights of children with ID. To this end, a study will be conducted on the practical situation of the promotion and protection of rights of children with ID.

Hence, the study will have the following significance:

- ❖ It identifies the intensity of problems faced by children with ID in exercising their rights recognized under international and national documents.
- ❖ It will create awareness about the rights of children with ID and also about the impact of violations of such rights among children with disability themselves, their families, schools, the community, etc.
- ❖ It highlights the possible areas of work for the government, NGOs' and any concerned body by pinpointing what rights, how and why these rights are being highly violated.
- ❖ It will also help as baseline information for further research conducted in this area.

1.7 Research Methodology

1.7.1 Method and tools of data collection

This research is a case study where ten families having a child with ID participated. Hence, the data gathering methods the researcher employed is qualitative. Interview guidelines were prepared and detail field observations were also conducted.

1.7.2 Sources of Data

The study is constructed with both primary and secondary sources of data. The primary sources include:

- ✓ children with ID,
- ✓ parents/guardians of the child with ID,
- ✓ other family members of the child with ID,
- ✓ neighbors of the child with ID,
- ✓ teachers and school director,
- ✓ Vision Community Based Rehabilitation Centre staff,
- ✓ government officials and
- ✓ health professionals.

International and domestic instruments, national and regional policies, various documents, including regional and zonal reports from concerned organs which include both governmental and NGOs were taken as secondary sources.

1.7.3 Sample size and sampling technique

In this study, 10 families having a child with ID are first selected. The sampling technique is purposive where the age and sex of the child with ID, educational background of the parents or guardians, financial capacity of the family and enrollment in school of the child with ID are taken in to account. This helps to create a clear link between disability and poverty, disability and education, etc. The participants are directly selected by the researcher with the help of W/ro Tamre Yigezu, a supervisor at VCBRA, since they are clients of the association. Four of the study participants are children below 5 years old. And the rest are above 5 and below 18. From the perspective of gender, half of them are girls and the rest half boys.

1.7.4 Data collection Procedure

To obtain a reliable data and get a picture of the case at hand the researcher collected the data in person. However, VCBRA has assigned two of its social workers for the home to home observation that the researcher conducted. The social workers took the researcher to their clients' home. Hence in addition to making it easier for the researcher to get those children with ID, they helped in creating smooth relationships between the researcher and their clients since they already know each other. Furthermore, the social workers assisted the researcher by giving the whole background of the participant family and their neighbors.¹⁴

The data collecting tool is first prepared in English and then translated in to Afan Oromo for communication purpose. The interview was conducted in a semi-standardized form. Hence, though there are guidelines that have a number of predetermined questions, the researcher was yet raising additional questions outside of the guideline where new and accidental issues were raised by the informants. Interview is conducted with 30 individuals. 10 Parents/guardians, 3 other family members of the child with ID, 6 neighbors, 4 VCBRA workers, 1 government official, 1 teacher, 1 school director, and 1 health professional were the interviewees. In the case at hand 3 of the study participants are able to communicate using few words. Hence, informal interview is conducted with those children with ID.

Field observation is conducted in a non-participant form, where the researcher was observing from the outside how the child with ID is living in the house, community, school, etc. It was conducted by visiting children with ID in their home in a separate occasion. The researcher was assisted by VCBRA social workers in conducting the field observation. The researcher and the social workers visited the study participants and their families.

1.8 Limitation of the Study

The researcher faced some obstacles, while conducting the research. The first is unwillingness of the parents and that of the neighbors to give information about the child with ID. Some of them expect financial aid as a reward, and hence it was a bit difficult to approach them. Others also say that the research will not ultimately have any direct impact on their children's life. Hence, they do not want to disclose what they consider personal issue of their family. In addition to these,

¹⁴ The social workers also know the clients' neighbors on the coffee ceremony to be held at their clients' house. See Chapter four page 50 Para. 2 of this thesis to have picture of the coffee ceremony.

some of the families were not in a position to discuss about the disability of their child especially thinking of it to be not having immediate relief for their current problem, like hunger. Hence trying to manage that at least for a while was found to be the researchers' duty before discussing anything about the ID and the child with ID. Be it as it may, the researcher and the social workers tried to convince them by mentioning the significance of the research and it is after getting the full consent of the informants that the data is collected.

Most of the informant children are either very young to communicate with or cannot easily understand what the questions forwarded to them are referring to, because of the disability itself. This is the other challenge that makes the researcher mostly depend upon the information provided by the parents/guardians and neighbors of that family. The other hindrance is related with financial problem. This research is conducted in Ambo city. Hence, the researcher has to travel to the city from Addis Ababa and stay there for days to collect data. Because of various reasons like bureaucracy of government officials and reasons related with parents/guardians of the child with ID, the researcher has to travel to Ambo city frequently.

1.9 Organization of the Study

This paper has five chapters. The first chapter is introductory which gives the background of the study, states the problem and provides the main research questions. It also includes the significance, the objective, the scope, organization and limitations of the paper. Chapter two is review of literatures. Chapter three is devoted to description of international, regional and domestic instruments, which includes policies and programs of Oromia regional state on rights of children with ID. Chapter four, the main part of this research paper provides analysis of the data collected on the implementation of the selected rights of children with ID in Ambo city. Chapter five, which is the last one, is summary of the findings, conclusions drawn from it and recommendations on the gaps figured out.

1.10 Ethical considerations

The study was conducted after getting support letter from Addis Ababa University to respective places including Social Affair Office of Ambo city, Vision Community Based Rehabilitation Association, school, Education Bureau and health centers. In addition informed consent was obtained from study participant to confirm willingness to participation in the study after

explaining the objective of the study. The participants were notified that the interview is conducted to obtain data for a research to be conducted by the interviewer and requested if they are willing to go through each questions or not. They were also informed that they have every right to refuse or terminate the interview. Pictures were also taken with the full consent of the interviewees, i.e. parents or guardians of the child. The information provided by each respondent is kept confidential.

Chapter Two: Review of Literatures

2.1 General overview of the concept of Intellectual Disability

Persons with disability, especially children with disability are marginalized groups of people. In most cases the marginalization is the result of misconception of the whole community and lack of awareness on the very concept of disability, the cause and above all the consequence of the stigma and discrimination against the child with disability. Hence, this chapter will define ‘intellectual disability’; discuss the causes and types of the disability. Furthermore, it will also show the link between ID and human rights on the one hand provide a detailed discussion on the duty bearers related with the rights of children with ID on the other.

2.1.1 Conceptual clarification of ID

Describing intellectual disability is hard. It is not something you are like being short or tall. It is not a medical disorder, although it may be coded in a medical classification of disease. Nor is it a mental disorder, although it may be coded in a classification of psychiatric disorder.¹⁵

In the past, people have often mixed ID with mental illness, brain injury, dementia and autism. There are also people who use stigmatizing and derogatory terms to describe persons with ID, for instance, mentally retarded, idiot, backward, feeble-minded, educationally subnormal,¹⁶ etc. The connotation behind such names is derogatory and currently these names are losing support. The name that has international acceptance these days is *Intellectual Disability*.¹⁷ Following this development, the American Association on Mental Retardation changed its name to "American Association for Intellectual and Developmental Disability (AAIDD)".¹⁸ From this we can see that, this new term is getting international acceptance. But it does not mean that this term has never been criticized rather it is said to have a defect of creating confusion, potential

¹⁵American Association on Mental Retardation(AAMR), *Mental Retardation: Definition, Classification, and System of Supports*, (9th ed.), AAMR, Washington, Dc, 1992, p. 9

¹⁶ *ibid* , table 1, labels, p-1

¹⁷ *Supra* note 4, p- 30

¹⁸ *ibid*

misinterpretation and lack of inclusiveness that this term conveys.¹⁹ However, its advantage weighs a lot and now it is being used in countries of the world replacing the term mental retardation²⁰

IDs and Physical Disabilities both fall under the umbrella term Developmental Disabilities. These are chronic conditions that appear at birth or in childhood, but certainly before age 22 and sometimes, but not always, occur together.²¹ Cerebral palsy, for example is physical disability, which in and of itself does not affect intellectual functioning, though 20-30% of individuals with Cerebral palsy also have a cognitive disability. Down Syndrome is the most common cause of ID, though levels of impairment vary widely.²²

There are lots of different ways to say what ID is, and this is called *definitions*.²³ Since 1937, AAMR is developing definition for the concept of mental retardation and it came up with new and modified definition by 1992.²⁴

"Mental retardation refers to substantial limitations in present functioning. It is characterized by significantly sub-average intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adoptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure and work. Mental retardation manifested before age 18."

In 2002 the AAMR Committee on Terminology and Classification prepared a new definition for ID which builds up on the 1992 AAMR definition by eliminating its criticisms. It states that:

¹⁹ *ibid*

²⁰ M, Beirne-Smith, J. R. Patton, S.H. Kim, *Mental Retardation, an Introduction to Intellectual Disability*, (7th ed.), Pearson Merrill Prentice Hall, New Jersey, 2006, p.45.

²¹ See at <https://www.arundellodge.org>, Kristin Lolmaugh, what is the difference between mental illness, developmental disability and intellectual disability? Accessed on 23/10/2018

²² *ibid*

²³ Anne Brey, *Definition of intellectual disability*, Review of the literature prepared for the national advisory Committee on Health and Disability to inform its project on services for adults with an intellectual disability, Donald Beasley Institute, National Health Committee, June 2003, p- iii

²⁴ *supra* note 4, p-31

“Mental retardation is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18.”

Further, five assumptions are essential to the application of this definition:

(1) *Limitations in present functioning must be considered within the context of community environments typical of the individual's age peers and culture.*

(2) *Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioral strengths.*

(3) *Within an individual, limitations often coexist with strengths.*

(4) *An important purpose of describing limitations is to develop a profile of needed supports.*

(5) *With appropriate personalized supports over a sustained period, the life functioning of the person with mental retardation generally will improve.*²⁵

As time went people realized that ID had something to do with how well people learn, i.e. *intelligence*.²⁶ Thus, clinically, and for the purpose of proving in a court that a person has an ID, it is best assessed by a psychologist as:

- Below average IQ, i.e. 70 or under, PLUS
- Deficits in at least 2 areas of adaptive behavior, i.e.
 - ✓ Communication
 - ✓ Self-care
 - ✓ Home living
 - ✓ Social skills
 - ✓ Self-direction
 - ✓ Leisure
 - ✓ Work and

²⁵ ibid

²⁶Supra note 18

✓ Learning ²⁷

A more constructive and pragmatic definition is to define ID in terms of the support needs of an individual. This approach, so called sociological approach, sees the effect of the disability as something that will vary and can be increased or decreased by external factors. It doesn't view ID as an unchangeable characteristic of the individual. This definition does not rely on the capacity of the person being set in stone, but also on the environment and the support that they receive.²⁸

Thus, having said this much about the conceptual definition of ID, for the purpose of this paper, a child with intellectual disability is:

a child under the age of 18 and is with disability characterized by significant limitations both in intellectual functioning (ability to learn, reason, make decisions, and solve problem) and adaptive behaviors (skills necessary for day-to-day life such as being able to communicate effectively interact with others, and take care oneself); and who needs the support of the society so to change, i.e. to learn, to know the day-to-day activities, give decision.. and lives in Ambo city.

2.1.2 Types of Intellectual Disability

Just like the definitions, the types of ID also differ based on who provides the classification. The sociological approach that focuses on the level of support demanded classified ID as; intermittent (as-needed basis); limited (consistent over time, time-limited); extensive (regular involvement); and pervasive (constant high intensity).²⁹

On the other hand, psychiatric classifications, based on severity of the delay in intellectual functioning, deficits in social adaptive function and IQ, describe **four** levels of severity.³⁰The

²⁷ Intellectual Disability Rights Service, *Introduction to Intellectual Disability*, Criminal Justice support Network, NSW 2016, Australia, p-2

²⁸Ibid

²⁹ supra note 4, p- 32

³⁰Ke X, Liu J. Intellectual disability. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012, p-5

second kind of classification is found out to be widely acceptable, hence, for the purpose of this research it will be taken as typology of ID.

There are four types of IDs and these are, Mild, Moderate, Severe and Profound.

2.1.2.1 Mild Intellectual disability

Children with mild ID have IQ result usually between 50 and 69 and account for about 80% of all cases. Development during their early life is slower than in normal children and developmental milestones are delayed. However, they are able to communicate and learn basic skills. Their ability to use abstract concepts, analyze and synthesize are impaired but can achieve reading and computing skills to grade three to six level. They can perform house-work, look after themselves and do unskilled or semiskilled work. They usually require some support.³¹

Mild ID is at the border of normality and disability so identifying those individuals with this type of intellectual disability is difficult. Children with such kinds of intellectual disability are not suspected until the child joins school. Adults with milder ID can secure employment and become economically self-sufficient.³²

2.1.2.2 Moderate Intellectual Disability

IQ is usually between 35 and 49, accounting for about 12% of all cases. They are slow in meeting intellectual developmental mile stones; their ability to learn and think logically is impaired but they are able to communicate and look after themselves with some support. With supervision, they can perform unskilled or semiskilled work.³³

2.1.2.3 Severe Intellectual Disability

IQ is usually between 20 and 34; severe ID accounts for 3% to 4% of all cases. Every aspect of their development in the early years is distinctively delayed; they have difficulty pronouncing words and have a very limited vocabulary.³⁴ Most of them have difficulty in

³¹ *ibid*, p-5

³² *Supra* note 4, p- 5

³³ *supra* note 23

³⁴ *ibid*

applying knowledge, limited communication skill and the rate of speech language disorder among this group is estimated at 90%.³⁵

An analysis of studies shows that 35% to 60% of the cause of ID is genetic disorder and more than half of severe intellectual disability is caused by genetically determined disorder.³⁶ Those persons with severe ID are victims of not being able to move their body freely. Most of them need assistance for mobility, for manipulating objects in their environment, for performing daily activities such as dressing, eating, toileting, and communicating. But some of them are able to do such daily activities with a great deal.³⁷ The major behavioral problems faced by those persons are verbally or physically aggressive acts, self-injury (head banging, hand flapping), non-compliance, self-stimulatory behavior (body rocking or repetitive vocalization), etc. Through considerable practice and time, they may gain basic self-help skills but still need support at school, home and in the community³⁸

2.1.2.4 Profound Intellectual Disability

IQ is usually below 20; profound ID accounts for 1% to 2% of all cases.³⁹ They are with undeveloped physical and mental development. As a result they face severe damage on their brain which controls all body activity. These persons are known of having a very small skull or very big skull full of liquid. Most of them die at childhood but those who survive do not show any improvement afterwards.⁴⁰

These persons are considered on the basis of current knowledge and practice, incapable of profiting from any type of training or education. They may be completely dependent on someone else for everything, including rolling over in bed, eating and toileting etc.⁴¹ Some of the characteristic of persons with profound ID are; they suck

³⁵HiwotAbebe, cited at note 106, p-34

³⁶United Nation Office of the High Commissioner for Human Rights, and Inter-Parliamentary Union, *From Exclusion to Equality: Realizing the Rights of Persons with Disabilities*, United Nation, Geneva, 2007, NO. 14, p, III.

³⁷HiwotAbebe, cited at note 107, p-34

³⁸ supra note 23

³⁹ ibid

⁴⁰HiwotAbebe, cited at note 109, p-35

⁴¹HiwotAbebe, cited at note 110, p-35

their thumb or finger, have night mares of difficulties in sleeping, have physical illness such as head ache, dizziness, eye strain, stomach upset, physically aggressive and never express their feeling, etc.⁴²

2.1.3 Causes of Intellectual Disability

Yet hundreds of causes of ID have been identified and it is still difficult to reach in to a general consensus because of the fact that it is only about 50% of causes of ID are specified. This problem of identification is highly related with mild ID.⁴³

In general there are three types of causes of ID.

Prenatal: -This stage being a stage that comes before birth, in human life, it is a stage in which life begins. The peaceful growth of the fetus could be disturbed and exposed to ID because of different factors that could be natural or artificial. One of the natural factors that cause ID at this stage is genetic disorder.⁴⁴The other natural factors that cause ID at this stage are Chromosomal Abnormalities and Blood-group incompatibility between the fetus and the mother.⁴⁵ The exposure of them to other toxic substances (research shows that 1 in 650 births from alcoholic mothers will be victim of ID), drugs, industrial chemicals, nicotine, caffeine, being infected by disease,⁴⁶ the exposure of the mother to accidents or falling, the age of the mother being very old or very early to conceive a child, etc.⁴⁷ All these factors have a direct effect on the fetus and results on different level of ID on the newborn baby.

Perinatal: -it is a time of delivery and a matter of few minutes or hours of duration, but crucial time in which ID may occur. Some of the causes are; at the time of delivery when the baby face shortage of oxygen (it is when the baby comes in improper position), when delivery is too early

⁴²Ethiopian Federation of Persons with Disability (EFPD), *Bright Hope: A Bilingual Annual Bulletin*, No.6. December 2002, p. 36

⁴³HiwotAbebe, cited at note 110, p-35

⁴⁴<http://www.searo.who.int/en/Section1174/Section1199/Section1567/Section1825>(Accessed on April 1, 2018).

⁴⁵HiwotAbebe, cited at note 110, p-36

⁴⁶<http://www.searo.who.int/en/Section1174/Section1199/Section1567/> (Accessed on April 1, 2018).

⁴⁷Ethiopian Federation of Persons with Disability (EFPD) (2003), cited at note 111, p. 17.

or too late from the regular time, the baby being under or over the normal weight, the improper usage of medical materials for pulling the baby, etc.⁴⁸

Postnatal: -After delivery there are lots of events that cause ID. Among them head injury takes the lead. It is estimated that 1 in 30 new born baby will experience a serious brain injury before completing ten year. And 89% of injuries are caused by falls mostly from bicycle or motorcycle.⁴⁹ Nutritional deficiencies of both the pregnant women and the new born baby, depriving environmental factors are also other factors.

2.2. Intellectual Disability and Human Rights

ID and problems of the victims of such disability can be approached from various perspectives. It could possibly be approached from biological, psychological, social, human rights or any other related perspectives. Hence, this paper will be looking at the case of children with ID from human rights perspective and before going to the details of the issue, it will first give a very short highlight on some important points on ID and human rights.

2.2.1 Why special protection for children with intellectual disability?

Children with ID are human beings endowed with all rights enjoyed by other human beings. So, audiences might be wondering why we are talking of their case as a special one that needs a special attention? Hereunder, the researcher will be providing some of the reasons for the need of having a special protection. But before that one has to bear in mind that while we say special protection we are not only referring to special and unique rights for children with ID. Rather it also refers to an equal opportunity and non-discrimination in all aspects of life. In fact, to this end, there might be a need to have a special arrangement since children with ID cannot equally be exercising their rights in the normal course of things. As per the general comment of the Committee to CESCR, there might be a need for affirmative action programs to reduce structural inequalities and to give appropriate differential treatment to these groups⁵⁰

⁴⁸ *ibid*

⁴⁹ Hiwot Abebe, cited at note 110, p-36

⁵⁰ CESCR General Comment No. 5, Persons with Disabilities. UN Document E/1995/22 1995 paragraph 9

Children with ID are first ‘children’ and second, they are ‘with disability’. This is what we call it ‘intersectionality’, a situation where a single individual is burdened with two or more issues that resulted to vulnerability of violations of human rights.

Because of their disability, children with ID are vulnerable to neglect, abandonment, and mistreatment.⁵¹As it has been mentioned under the first chapter of this thesis, families of these children and the community at large have a negative perception towards children with ID. They even go to the extent of considering the child as a curse.⁵² In addition to this mistreatment, the disability by itself hampers and decreases the capacity of the child to understand issues, learn, and also work. Hence, this makes them rely on the helps of other people than any other kind of physical disability.

Therefore, protecting the violations of rights of these children, using the existing human rights documents that are common for all is hardly possible. Hence there is a need to have a special protection and a special arrangement to address problems of children with ID and help them enjoy their rights equally.

2.2.2 Duty Bearers and Stakeholders in the Realization of Rights of Children with Intellectual Disability

While discussing about the right of children with ID, it is essential to know from whom to claim these rights (the rights will be discussed in detail under chapter three of this thesis.) To begin, this research is focusing on some selected rights that are listed under the first chapter and also to be discussed. These are rights to family life, social inclusion, and education; participate in play and recreation, leisure, the best possible health, an adequate standard of living/protection from poverty, and protection from discrimination, all forms of violence and abuse. In the process of realization of these rights there are different stakeholders and duty bearers. Some of these duty bearers and stakeholders are,

A. States having obligations under international and national laws

⁵¹ M.J. Chomba et al, Education of students with Intellectual disability in Kenya: Challenges and prospects, vol 34, No 4 (2014), p- 16

⁵² Supra note 4

- B. Parents or guardians of the child, in their absence,
- C. the Community at large
- D. Human right organizations in protecting and promoting human rights.

A. States Obligation under International law

States Parties [to international human rights] have the primary obligation to respect, protect and fulfill the [...] rights of all persons under their jurisdiction in the context of corporate activities undertaken by state-owned or private enterprises.⁵³ Signatory states of international human rights instruments in general and the CRPD in particular have the following obligations.

The obligation to respect – States parties must refrain from interfering with the enjoyment of the rights of persons with disabilities.⁵⁴ For example, in the case at hand States must not perform medical experiments on children with intellectual disabilities without their consent or exclude them from school on the basis of disability.

The obligation to protect – States parties must prevent violations of these rights by third parties.⁵⁵ For example, States must be diligent in protecting children with ID from mistreatment or abuse by their family, the community and school compound. It should also protect them from poverty and discrimination

The obligation to fulfill – States parties must take appropriate legislative, administrative, budgetary, judicial and other actions towards the full realization of these rights.⁵⁶ For instance the government shall enact special laws and ratify international documents that are relevant for the

⁵³Committee on Economic, Social and Cultural Rights, *Statement on the obligations of States Parties regarding the corporate sector and economic, social and cultural rights*, UN Doc. E/C.12/2011/1 of 20 May 2011, Para. 3

⁵⁴Andrew Byrnes et al, *From Exclusion to Equality, realizing the rights of persons with disability*, No. 14, 2007, p-20. It is a handbook for parliamentarians on the Convention on the Rights of Persons with Disabilities and its Optional Protocol and was jointly prepared by the Department of Economic and Social Affairs (UN-DESA), the Office of the United Nations High Commissioner for Human Rights (OHCHR) and the Inter Parliamentary Union (IPU)

⁵⁵ *ibid*

⁵⁶ *ibid*

issues of a child with ID. It shall also allocate a sufficient budget for the protection and promotion of rights of children with ID

The above discussed obligations being general obligations, CRC also provides an explicit obligation upon state parties related to children with mental disability. It requires state parties

*...to recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community*⁵⁷ Thus, state parties shall be diligent enough to realize the rights of children with ID by promoting and protecting their rights as it is expected of them.

B. Parents or guardians of the child

Families provide a significant level of support and care for their child with disability as well as enabling them to participate in community life.⁵⁸ Parents of a child are the very first responsible persons for the upbringing and the day to day protection of their children. CRC, to which Ethiopia is a party, asserts that state parties shall recognize the right of every child to standard of living adequate for the Child's physical, mental, spiritual, moral and social development.⁵⁹ The parent(s) or others responsible for the child have the primary responsibility to secure, within their abilities and financial capacities, the conditions of living necessary for the child's development.⁶⁰ Hence, it is important that governments promote policies that support family life and in particular provide assistance to families with children with disability (for example promoting employment practices which enable parents to combine work with providing care to their child with disability).⁶¹

⁵⁷ See article 23 of CRC

⁵⁸ European Coalition and Community Living (ECCL), Focus on the rights of children with disability to live in the community, focus report, 2006, p-8

⁵⁹ See article 27/1 of CRC

⁶⁰ See article 27/1 of CRC

⁶¹ Supra note 50

C. The Community

While we talk of a right of one person, in effect we are also referring to the duty of another. Children with ID shall enjoy all rights enjoyed by other children without such disability. To this end, the community at least is obliged to respect the rights of children with ID. The community shall be restricted from interfering on personal life of children with ID by discriminating and labeling them as retarded and idiot. It shall also be prohibited from being engaged on any kind of activity that will hurt the psychology of the child with ID (for instance neighbors shall not consider the child as an insane or a curse and prohibit their children from playing with a child with ID.)

D. The role of Non-governmental Organizations in promoting and protecting human rights

Many organizations around the world dedicate their efforts to protecting human rights and ending human rights abuses. Major human rights organizations maintain extensive websites documenting violations and calling for remedial action, both at governmental and grass-roots level.⁶² Public support and condemnation of abuses is important to their success, as human rights organizations are most effective when their calls for reform are backed by strong public advocacy. Non-governmental organizations (NGOs) are known for their works on human rights.

NGOs are part of ‘civil society’, which is broader that includes churches, religious associations, trade unions, interest groups, and organizations of employers.⁶³ There are different types of NGOs which includes, international and national, main-stream or focused on selected issues, grass roots’ organizations, different scope of activities, activist organizations vs. think tank organizations, NGOs acting in a public interest vs. NGOs pursuing particular interest (e.g. lobbying NGOs)⁶⁴

⁶² Human rights organizations, at www.humanrights.com accessed at 05/02/2018

⁶³ Adam Bodnar, the role of NGO in the protection of human rights, Helsinki Foundation for Human Rights, Poznan, 6 September 2001

⁶⁴ *ibid*

The champions of human rights have most often been citizens, not governments, globally.⁶⁵ In particular, NGOs have played a primary role in focusing the international community on the human rights issue. They monitor the actions of governments and pressure them to act according to human rights principles⁶⁶ Some of these groups which work at international level include; Amnesty International, Human Rights Watch, children's Defense Fund,⁶⁷ etc. Most important features of NGOs dealing with human rights are Credibility, Public trust and confidence, Responsiveness, Independence, and Dynamism. This is because NGOs may have impact but they do not make political decisions. They are responsible before the society and their sponsors; and are also transmitter of views of the society to the government.⁶⁸

There are four basic methods applied by NGOs in promoting and protecting human rights. These are monitoring, advocacy, strategic litigation and education. By monitoring we are referring to the role of NGOs as a watch dog and through the application of which they control the government and other institutions (also private institutions.) On the other hand, advocacy is arguing on behalf of a certain issue, idea or person as a result of which they change the attitude of government, Show the problem and Convince the society. Strategic litigation conducted to make significant changes in law or legal practice through litigation of the carefully selected cases⁶⁹

The last method, education on human rights is an important element of NGOs' activities and is a priority for many organizations. In some countries it is the only method to advance human rights. Education has only indirect and long-term impact on human rights' protection.⁷⁰

2.2.3 Immediate and Progressive Realization of rights of Children with Intellectual Disability

Realizations of human rights in general are the primary responsibility of states. However, in most cases states are known for defending themselves based on the progressive realization of some

⁶⁵ Supra note 54

⁶⁶ ibid

⁶⁷ ibid

⁶⁸ Supra note 54

⁶⁹ ibid

⁷⁰ ibid

rights while there is non-compliance. Hence, the primary aim of the discussion up on this sub-topic is not to show the difference between the immediate and progressive realization of rights, rather it is to show how the so called progressively realized rights also have an immediate character deep inside.

CCPR obliges state parties to undertake to respect and to ensure to all individuals within its territory and subject to its jurisdiction the rights recognized in the present Covenant, without distinction of any kind, such as race, color, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.⁷¹ This shows the fact that civil and political rights are immediately realizable and not resources dependent. On the other hand, CESCR obliges state parties to undertake to take steps, individually and through international assistance and cooperation, especially economic and technical, to the maximum of its available resources with a view to achieving progressively the full realization of the rights recognized in the covenant by all appropriate means, including particularly the adoption of legislative measures.⁷²

The CESCR which is tasked with monitoring state party's compliance with their obligations under the covenant has emphasized that Article 2(1) above is of particular importance to a full understanding of the Covenant and must be seen as having a dynamic relationship with all other provisions of the Covenant as it describes the nature of the general legal obligations to be undertaken by the state parties to the Covenant⁷³

The notion of progressive realization reflects the nature of states obligations in respect of [economic, social and cultural rights] in so far as the level of a country's economic development determines the level of its obligations in respect of any of the rights of the Covenant.⁷⁴ This introduces a flexibility mechanism which implies that the obligation of states parties vary from

⁷¹ See article 2 of ICCPR

⁷² See article 2 of ICESCR, Similar provisions on progressive realization are set out in Article (4) of the Convention on the Rights of the Child; Article 4(2) of the Convention on the Rights of Persons with Disabilities

⁷³ ICESCR General Comment No. 3: 'The Nature of States Parties Obligations' 1990

⁷⁴ As cited in Esther Kinya Rintari, A Critical Analysis of the Implementation of the Principle of Progressive Realization of Economic, Social and Cultural Rights: A Comparative Study of the progressive realization of the right to adequate housing in Kenya and South Africa, University of Nairobi School of Law, 2014, p-20

one state party to another and that even in respect to a state party some of its obligations may vary over time⁷⁵

In attempting to elaborate comprehensively the concept of progressive realization this paper emphasizes three issues, firstly, there has to be immediate and tangible progress towards the realization of the rights and although progressive realization allows the state party room for flexibility in the enforcement of ESCRs it does not provide a green light to drag its feet.⁷⁶ The principle of progressive realization cannot be interpreted as implying that states defer efforts to ensure progressive realization of ESCRs but are instead required to immediately put in place measures aimed at fulfilling their obligations under the Covenant.⁷⁷ In the context of the ICESCR, each state party has an obligation to take steps towards progressive realization within a reasonably short time after entry into force of the Covenant for the state in question. Related to the issue of flexibility is that the state is also obligated to take measures that are flexible so as to adapt to its changing circumstances⁷⁸

Secondly, a state party cannot purport to take deliberate retrogressive measures. There is an immediate obligation on the state to ensure constant improvement in the realization of ESCRs and retrogressive measures are not permissible under the Covenant and if taken they have to be justified by reference to the totality of rights. The obligation requires that state parties take more steps even where people already have access to ESCRs to improve the nature and quality of services to which people have access⁷⁹

Thirdly, progressive realization requires that special measures be taken by the state party in respect of the vulnerable and marginalized or disadvantaged groups in society which measures as was discussed in the theoretical framework are underpinned by the Rawlsian theory of distributive justice. The state parties are required to do more than refrain from taking retrogressive measures.

⁷⁵ *ibid*

⁷⁶ Esther KinyaRintari, *A Critical Analysis of the Implementation of the Principle of Progressive Realization of Economic, Social and Cultural Rights: A Comparative Study of the progressive realization of the right to adequate housing in Kenya and South Africa*, University of Nairobi School of Law, 2014, Pp, 20-21

⁷⁷ Limburg Principles on the implementation of the ICESCR. UN Doc E/en4/t 987/17, paragraph 21

⁷⁸ *Supra* note 54, p-21

⁷⁹ *Ibid*

It is expected to put in place affirmative action programs to reduce structural inequalities and to give appropriate differential treatment to these groups⁸⁰

2.2.4 Poverty and Intellectual Disability

Decades of research have carefully documented the association between ID and poverty.⁸¹ But why is this association important to this research? In understanding the life experiences of people with ID, for centuries there is a consensus that their exposure to poverty is associated with poorer health and restricted life opportunities.⁸² More recently, findings show much more about the role of exposure to poverty (and its associated adversities) in childhood on health and well-being across the life course, the biological processes through which this experience gets “under the skin,” and the fundamental importance of these “social determinants” to understanding the inequitable distribution of health and social opportunities within populations⁸³

The CRPD recognizes the right of persons with disabilities to social protection without discrimination, including access to food, clothing, clean water, affordable services, and devices and other assistance for disability-related needs, social protection and poverty reduction programmes, adequate training, counseling, financial assistance and respite care, public housing programmes, social welfare programmes and retirement benefits.⁸⁴

The inextricable link between poverty and disability can be shown as follows:⁸⁵

- Children who are poor are more likely to become disabled through poor healthcare, malnutrition, lack of access to clean water and basic sanitation, dangerous living and working conditions.⁸⁶ Specifically, there is a significant research to suggest that people living at or under lines are at increased risk of developing or passing on an ID. This can be traced to reduced options regarding healthcare, education, living standards and general safety.⁸⁷

⁸⁰ Supra note 43

⁸¹ Eric Emerson et al, Intellectual disability and poverty: Introduction to the special section, *Journal of Intellectual & Developmental Disability* · December 2010, p- 221

⁸² *ibid*

⁸³ *ibid*

⁸⁴ See article 28 of CRPD

⁸⁵ UNICEF, *Children and young people with disability, unite for children*, May, 2013, p-16

⁸⁶ Supra note 72

⁸⁷ See <http://www.enotes.com>, Accessed on 21st of April 2018.

- A disproportionate number of all persons living in poverty in developing countries are persons with disabilities⁸⁸

- Children with disabilities are more likely to be poor throughout their lifetimes, due to lack of education, exclusion from apprenticeships or job training programmes, and exclusion from employment and micro-credit efforts. In both developed and developing countries, households with disabled members are likely to be poorer than those without, because of increased expenses and the likelihood of a member of the family having to give up work to provide care.⁸⁹ Particularly, as a family with intellectually disabled child might find themselves sliding in to the poverty line directly because of that member, either because of financial costs or because of social stigma.⁹⁰

- People with less severe intellectual disabilities, and the families that support them, are much more likely to be located in lower socioeconomic positions and to experience poverty.⁹¹
- Recent research has also suggested that people with more severe intellectual disabilities may also be at greater risk of experiencing poverty, although the strength of the association is clearly far weaker.⁹²
- Many health insurance schemes discriminate against persons with disabilities, on grounds of the cost of their health care.⁹³ Social protection schemes often fail to take account of the additional costs associated with a child with disability. Basic disability benefits rarely provide adequately for both basic household expenses and extra costs related to disability, resulting in families being driven into poverty. Furthermore, cash transfer and social health protection schemes often require compliance with conditions that children with disabilities cannot fulfill, such as regular attendance at school, from which a child may have been denied access. This kind of discrimination or stigma may possibly be a

⁸⁸Elwan, A. *Disability and poverty: a survey of the literature*. Washington, DC: World Bank, 1999

⁸⁹ Supra note 73

⁹⁰ Supra note 81

⁹¹ Supra note 77

⁹² *ibid*

⁹³ Jeanine Braithwaite and Daniel Mont, 'Disability and Poverty: a survey of World Bank poverty assessments and implications, World Bank, Washington DC, and February, 2008.

problem of developed countries. The researcher discussed the issue to show the intensity of the problem. But there is no clearly identified relevance for the case at hand since insurances, cash transfer and social health protection schemes are not experienced by the informants.

Generally speaking, poverty is a major contributory factor leading to disability while disability traps people into poverty. Hence, the state of poverty increases the chance of ID, just as being with ID increases the chance of poverty. Correlation and causation strengthens each side, both harming the individual and family unit.⁹⁴

Conclusion

The concept of ID is hard to describe. It is not a concept to be understood easily as being short or tall. It is a very complicated concept which is defined by various scholars from their own perspective. The two known perspectives are medical approach and social model approach; and for the purpose of this research the social model approach that relates the disability with external factors is given a higher emphasis and the definition is taken as a functional/working definition of ID. Related with the types of ID, though there are many classifications based on who classified the concept, the medical approach classification is the well known one. It is also a classification that is discussed in detail within this thesis. According to this approach, ID is classified in to four, i.e. mild, moderate, severe and profound ID. ID is encountered by individuals at different stage of life and for different reasons. These are prenatal, perinatal and postnatal.

The researcher studied ID from the human rights perspective. Hence, this chapter discusses the need to have a special protection for children with ID, duty bearers and stakeholders, the case of progressive or immediate realization of rights of children with ID and the link between poverty and ID.

⁹⁴ Supra note 73

Chapter Three: Selected Rights of Children with Intellectual Disability under International, Regional and Domestic Instruments

Human rights are universal by their nature and their universality is elaborated by different scholars conceptually, substantively, historically, and functionally. Be it as it may, there are international and national laws that recognizes human rights to which Ethiopia is a party.

The general aim of this chapter is to show how some rights, selected by the researcher after conducting exploratory investigation (See pages 4 Para. 4 and page 5 Para. 1 of this paper) on the issue, are incorporated and recognized under international and national human rights instruments. To this end, international instruments (UDHR, CCPR, CECSR, CRC and CRPD); regional documents (ACHPR and its protocol on persons with disability; and ACRWC) and national laws (the FDRE and the Oromia Regional Constitutions, other related legislations, policies, programs and Action plans at regional level) have relevance. In addition to this, Declaration on the Rights of Mentally Retarded Persons and The Standard Rules on the Equalization of Opportunities for Persons with Disabilities will be cross-referred if a need arises. As it is necessary to understand the concept well, general comments of treaty bodies will also be reviewed.

The paper on the international, regional and national legislations related to rights of children with disability in general and children with ID in particular. All the international and regional instruments discussed here under are signed and ratified by Ethiopia, and hence are the integral part of the law of the land as per Articles 9/4 and 13/2 of the FDRE Constitution.

3.1 International Instruments

Being human suffices to enjoy the human rights recognized under international laws. Thus, Bill of rights and other treaties that specifically address the case of children with disability will be of relevance. However, since a detailed discussion of each document will not have a significant

impact on this thesis, recognizing the relevance of all documents, the author will only focus on the documents that are directly addressing the issues of children with ID.

3.1.1 Convention on the Rights of the Child

The principles of human rights mentioned in different international human rights instruments and frameworks apply both to children and adults. However, a separate instrument like the Convention on the Rights of the Child brings together children's human rights articulated in other international instruments. Therefore, in 1989 the various ideas embodied in international instruments such as, UDHR, ICESCR, ICCPR and similar international instruments culminated in the United Nation Convention on the Rights of the Child.⁹⁵CRC is a document that sets out the rights which must be respected for all children, including children with disability. Under article 23 CRC sets out the specific obligations that States must comply with in respect of children with disabilities.

The General Comment No.9 on the Rights of Children with Disabilities provides the interpretation of CRC by the Committee on the Rights of the Child, as it relates to children with disabilities, and the Committee's recommendations as to how they should be implemented by governments. It therefore provides more detailed guidance to governments on how to implement the rights of children with disabilities. Other General Comments of the Committee on some provisions of the CRC are also relevant to children with disabilities. For example General Comment No. 8 on Article 19 and 28 of CRC is relevant on this case.

While discussing why it is making the General Comment, the Committee notes that children with disabilities are still experiencing serious difficulties and facing barriers to the full enjoyment of the rights enshrined in the Convention. The Committee emphasizes that the barrier is not the disability itself but rather a combination of social, cultural, attitudinal and physical obstacles

⁹⁵Tilahun Teshome, "The Child and the Law in Ethiopia: The case of the United Nations Convention on the Rights of the Child", *Journal of Ethiopian law*, Vol. XVIII., 1989, p. 37-38.

which children with disabilities encounter in their daily lives.⁹⁶The general comment is meant to provide guidance and assistance to States parties in their efforts to implement the rights of children with disabilities, in a comprehensive manner which covers all the provisions of the Convention.⁹⁷

The Convention is predicated on four cardinal principles which are meant to help with the interpretation of the Convention as a whole and thereby guide national programs of implementation.⁹⁸ These principles are also fundamental principles of the ACRWC. Hence, to avoid repetition the author will be presenting the principles by cross referring to both the Convention and the Charter.

The cardinal principles are:

- *non-discrimination* (article 2 of the Convention, article 3 of the Charter);
- *best interests of the child* (article 3 of the Convention, article 4 of the Charter);
- *right to life, survival and development* (article 6 of the Convention, article 5 of the Charter); and
- *The views of the child* (article 12 of the Convention, article 6 (2) of the Charter).

The essence of the non-discrimination principle is equality of opportunity for children of both sexes, refugees, foreign origins, indigenous or minority groups and children with disabilities. The best interest of the child principle connotes the yardstick for measuring all the actions, laws and policies of a state affecting children. It has been argued that the term *development* in the right to life, survival and development principle should be interpreted in a broad sense, adding a qualitative dimension, such that not only physical health is intended, but also mental, emotional, cognitive, social and cultural development. The underlying idea of the *views of the child*

⁹⁶Committee on the Rights of the Child, General Comment No. 9, ‘the rights of children with disabilities’, CRC/C/GC/9, 2006, Para. 5

⁹⁷Ibid, CRC/C/GC/9, Para. 6,

⁹⁸DejoOlowa, Protecting children’s rights in Africa: A critique of the African Charter on the Rights and Welfare of the Child, *Department of Public and International Law, Faculty of Law, University of Ibadan, Ibadan, Nigeria, The International Journal of Children’s Rights* **10**: 127–136, 2002, p-129

principle is that children have the right to be heard and to have their views taken seriously in any proceedings affecting them.⁹⁹

Though providing a deep discussion on these four cardinal principles will have its own significance, since the Concept will one way or another be raised while discussing rights protected, it suffices to give a general clue of each principles to avoid unnecessary repetition.

3.1.2 Convention on the Rights of Persons with Disability

It was in December 13, 2006, that the United Nations General Assembly formally adopted the Convention on the Rights of Persons with Disabilities at the United Nations Headquarters in New York, and was opened for signature on 30 March 2007.¹⁰⁰The Convention came into force on 3 May 2008 with the aim of promoting, protecting and ensuring the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and promoting respect for their inherent dignity.¹⁰¹

The Convention has three unique features. First, the way it was developed makes it unique i.e. it was for the first time in the history of the United Nations that people with best interest with the Convention were so intimately involved in drafting. And also the disability community influenced not only the text itself, but also the level of awareness among member states of the challenges faced by people with disabilities and their families. Second, it shifts the understanding of disability from a medical to a social model (in which disability is no more seen as a problem rather a set of barriers). Further, it also includes articles that require state parties to develop social policies and practice overtime. Third, it is the first core human right Convention to have links to both the United Nations Office of the High Commissioner on Human Right and the United Nation Department of Economic and Social Affair¹⁰²

⁹⁹ *ibid*

¹⁰⁰ *Supra* note 4, p 47

¹⁰¹ See article 1 of CRPD

¹⁰² *Supra* note 4 , p 48

The Convention protects all persons with disabilities, who are defined in Article 1 as including ‘... those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.’ This broad definition adopts what is known as the *social model* of disability.¹⁰³ It recognizes that disability is an evolving concept, and that [persons with disability] are often prevented from exercising all of [their] human rights and fundamental freedoms by barriers of attitude and environment which have been placed in [their] way.¹⁰⁴ Article 8 of the Convention takes the social model further by obliging countries to adopt measures to raise awareness of the rights of persons with disabilities to combat "stereotypes, harmful practices and prejudices."

The CRPD is a document that builds on the CRC to introduce specific measures needed to protect the rights of people with disabilities including children with ID. In fact, none of the rights recognized under this document are new, rather, they introduce obligations on governments to remove the barriers that currently impede the realization of the rights of children with disabilities.¹⁰⁵ The committee on CRPD also prepared different General Comments on different agendas. This includes General Comment no. 4 on the rights of inclusive education (Article 24) and General Comment no. 5 on Equality and Non- discrimination (Article 5.)

3.1.3 The Standard Rules on the Equalization of Opportunities for Persons with Disabilities

Among the major outcomes of the United Nations Decade of Disabled Persons (1983- 1992) was the adoption, by the General Assembly, of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities in 1993.¹⁰⁶ The primary aim of the United Nations General Assembly was to agree on an international convention on the elimination of all forms of discrimination against persons with disabilities but because of lack of consensus it was rather

¹⁰³ Pr. Emeritus Ron McCallum, The UN Convention on the Rights of Persons with Disability, International Paralympic Committee, p 3

¹⁰⁴ *ibid*

¹⁰⁵ Gerison Lansdown, guide to using the UN Convention on the Rights of Persons with Disabilities to promote the rights of children, SEE ME HEAR ME, Save the Children, 1 St John’s Lane, London EC1M 4AR, UK, p 67

¹⁰⁶ *Supra* note 3, p 51

agreed to formulate the non-binding Standard Rule on the basis of the experience gained during the UN Decade of Disabled Persons.¹⁰⁷ The purpose of the Rule is to ensure that persons with disabilities can exercise the same rights as other persons. Although not a legally binding instrument, the Standard Rules represent a strong moral and political commitment of governments to take action to attain equalization of opportunities for persons with disabilities. The rules serve as an instrument for policy-making and as a basis for technical and economic cooperation.¹⁰⁸

The Standard Rules consist of 22 rules divided in to four chapters that cover the whole aspects of life of persons with disabilities; precondition for equal participation, target areas for equal participation, implementation measures, and the monitoring mechanism. In its resolution 49/153 of 1994, The General Assembly urged all governments to implement the Standard Rules and welcomed the appointment of a Special Rapporteur to monitor the implementation of the Rules. World Health Organization supports in particular the implementation of the United Nation Standard Rules and promotes their use for the development of national policies related to disability and rehabilitation.

The Standard Rule, in its preamble, gives due emphasis to the need to make an intensified effort to achieve the full and equal enjoyment of human rights by persons with disabilities. And it also makes reference to different International Human Rights Instruments such as, UDHR, ICCPR, CRC, etc.

3.1.4 Declaration on the Rights of Mentally Retarded Persons

The Declaration on the Rights of Mentally Retarded Persons was adopted by the United Nations General Assembly in Resolution 2856(XXVI) of 20 Dec, 1971. Although the Declaration is not legally binding, it does have power of moral and political situation which were used effectively to bring national policy changes. It was underpinned by a desire to assist persons with

¹⁰⁷Drouglas Hodgson, *The Human Right to Education*, Faculty of Law, The University of Western Australia, Ashgate publishing ltd, England, P 159

¹⁰⁸ Supra note 4, p 52

intellectual disability to develop their abilities in various fields and to promote their integration as far as possible in normal life.¹⁰⁹

The Declaration consists of a Preamble with seven paragraphs and eight Articles. The preambles of the declaration specifies the need of giving due emphasis on the protection of persons with intellectual disability. Article 1 stated that: "*The mentally retarded person has, to the maximum degree of feasibility, the same rights as other human beings*". This is a general provision which deals about the right of persons with ID to enjoy all the rights without any discrimination same to other human beings. This shows that, persons with ID, except their limited capacity of performing some activities, are no different creatures and it entitles them to enjoy all the rights that belong to other human beings.

3.2 Regional Documents

The African Charter has got single provision for issues related to disability. It stipulates that Persons with disability shall have the right to special measures of protection in keeping with their physical or moral needs.¹¹⁰ This provision shows the need of having a special arrangement for persons with disability to enjoy their rights equally. Under this sub topic the ACRWC and the draft protocol on persons with disability will be provided a higher emphasis since these documents directly address issues of children, and persons with disability respectively.

3.2.1 African Charter on the Rights and Welfare of Child

It has been contended that the Charter was born out of the feeling by African member-states that the Convention on the Rights of the Child missed important socio-cultural and economic realities of the African experience. It must however be recognized that the Charter is not opposed to the Convention; rather, the two pieces of legislation are complementary and both provide the framework through which children and their welfare are increasingly discussed in Africa. Whereas the Convention generally makes it clear that children are independent subjects and have

¹⁰⁹ Supra note 96, p 156

¹¹⁰ See article 18/4 of ACHPR

rights, the Charter stresses the need to include African cultural values and experience in considering issues pertaining to the rights of the child in Africa.¹¹¹

The Charter is made up of three broad parts.¹¹² The Preamble is couched in the traditional format, providing the logic for the adoption of the Charter. Part I deals with the substantive provisions on the rights of the child, while Part II covers the safeguard machinery and temporal provisions. For the enjoyment of the rights set forth in its provisions, the Charter imposes a lot of responsibilities on states parties. Generally under its article 1, states parties are expected to put in place the necessary machinery for the enjoyment of these rights and to remove any limiting factors. The Charter also establishes certain rights that are part of either customary law rules or general principles of international law. Like its forerunner, the Charter makes elaborate provisions for the protection and promotion of the rights and welfare of children.¹¹³

The Charter is known for having its own distinctive features. For instance, the Charter advanced the status of socio-economic rights beyond the traditional confines of rights which are considered only attainable by “progressive realization”. To this end, the guarantee of the rights to education (article 11); to leisure, recreation and cultural activities (article 12); health and health services (article 14); and freedom from economic exploitation (article 15) all amount to a bolder expression of their equivalents in the International Covenant on Economic, Social and Cultural Rights of 1966.¹¹⁴ It is also remarkable that the Charter is devoid of inbuilt limitations otherwise known as “claw-back clauses” which have whittled down the normative potentials of the African Charter on Human and Peoples’ Rights of 1981.¹¹⁵

Perhaps the most remarkable landmark in the Charter is in the framework of its implementation mechanism. The Committee of Independent Experts, the treaty body responsible for the supervision and monitoring of the implementation of the Charter provisions (the Committee) has broad interpretative and promotional mandates and thus, it cannot only clarify Charter provisions but can also formulate principles and rules aimed at the promotion of the rights of the child in

¹¹¹ Supra note 91, P 128

¹¹² Ibid

¹¹³ ibid

¹¹⁴ Ibid, p 130

¹¹⁵ Ibid

Africa.¹¹⁶ This has been identified as a wide-ranging power that would allow the Committee to draft a checklist of fundamental principles on the rights of the child which could become useful tools in legislative drafting at domestic levels. It could also positively influence the formulation of national policies.¹¹⁷

3.2.2 Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa

The African Commission on Human and Peoples Right (ACHPR) has adopted a draft protocol on the rights of persons with disabilities (herein after called 'the Protocol'), intended to complement the ACHPR and address continued exclusion, harmful practices, and discrimination affecting those with disabilities, especially women, children, and the elderly.¹¹⁸ By now this protocol is adopted at the African Union Summit in Addis Ababa, Ethiopia, on 29 January, 2018.¹¹⁹ The protocol, adopted during the ACHPR's 19th Extraordinary Session culmination of the African Union's focus on the rights of persons with disabilities, which began in 1999 with the declaration of the African decade for persons with disability and the creation of a Working Group tasked with drafting this new instrument.¹²⁰ The protocol guarantees equal protection of economic, social, cultural, civil, and political rights to individuals with "physical, mental, intellectual, developmental or sensory impairments" and will require States parties to implement affirmative action's to advance their equality.¹²¹

The intent in drafting the protocol was to lay out the rights of persons with disabilities in continental context, drawing from the United Nations Convention on the Rights of Persons with Disability but also addressing additional issues specific to Africa. The protocol, accordingly,

¹¹⁶ See article 42 of ACRWC

¹¹⁷ Supra note 91, p 131

¹¹⁸ See <http://www.ijrcenter.org> accessed on April 15, 2018. (African Commission adopts draft protocol on Persons with Disabilities' Rights, International Justice Resource Centre)

¹¹⁹ See <https://www.ohchr.org> accessed on September 22, 2018 (African states affirm the rights of persons with disabilities in a new landmark Protocol)

¹²⁰ Ibid

¹²¹ See art. 1(g) of the Draft Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa adopted on 25 February 2016.

addresses issues faced by persons with disabilities in Africa, such as increased rates of poverty; systemic discrimination; and risk of violence and abuse, particularly for those with albinism and women and girls with disabilities.¹²² The protocol also seeks to provide a foundation from which Member States can formulate or adjust legislation impacting persons with disabilities.¹²³ The ACHPR has in the past found State law on persons with disabilities incompatible with international norms.¹²⁴

The protocol requires States parties to ensure that people with disabilities are not discriminated against and enjoy equality. It recognizes the particular vulnerabilities and rights of women, children, youth, and older persons with disabilities. Additionally, the protocol extends rights to family and caregivers of people with disabilities who might otherwise be subject to discrimination as a result of their association. The protocol recognizes the specific protection needs of disabled people in periods of armed conflict or other humanitarian situations, as well. The protocol specifically requires States to take necessary steps to promote equality and to provide reasonable accommodations. These affirmative steps and special measures are not being considered discrimination, pursuant to the text. This positive obligation specifically applies to access to basic economic and social spheres, such as employment under just and favorable conditions, education, and health care and conditions of health. People with disabilities are also guaranteed rights to equal opportunity to participate in politics and governance, liberty and humane treatment, free speech and expression, and access to justice.¹²⁵

3.3 Domestic Laws and policies of Ethiopia

The government of Ethiopia has tried to take a number of policy and legislative steps that indicates commitment to advancing the rights of persons with disability. It has ratified international and regional documents; and it has also proclaimed its own laws to promote and protect rights of persons with disability in general which includes children with ID.

¹²² Ibid, @ preamble

¹²³ ibid

¹²⁴ Supra note 116

¹²⁵ Ibid

3.3.1 The FDRE and Oromia Regional Constitutions

The FDRE and Oromia Regional Constitutions are entirely all the same regarding the protection and promotion of rights of children with ID. Even the articles where the issues of disability and children in general are enshrined are the same under these two Constitutions.

The two Constitutions mentioned disability under Article 41/5 which provides that the State shall, within available means, allocate resources to provide rehabilitation and assistance to persons who are ‘physically and mentally disabled.’

Appreciating the concern, the author has got a number of problems with this kind of stipulation. First the phrase ‘physically and mentally disabled’ by itself is an outdated and degrading for persons with disability. The formulation of the provision would better be framed based on the social model of disability; just like that of CRPD. Second this provision is found under the sub-topic of ‘Economic, Social and Cultural rights’ in both the FDRE and Oromia Regional Constitutions. Hence, it is apparent that the constitutions disregard the civil rights of children with disability. True that these two Constitutions recognizes that all persons are equal before the law and entitled without discrimination to the equal protection of the law.¹²⁶ But still, the Constitution is short of explicitly protecting children with disabilities against discrimination, though the phrase ‘*other status*’ includes disability.

Once again, though rights of children are recognized within these Constitutions, it is categorized under part two, Chapter three of the same Constitutions, i.e. ‘Democratic Rights.’¹²⁷ The author finds no reason for such absurd categorization of rights of children under the so called ‘Democratic Rights.’ Surprisingly, no sub-provision is devoted to the equal and non-discriminatory enjoyment of rights of children with disability. It is only through interpretation and cross-reference to Article 25 (principle of equality) that children with disability are protected from discrimination.

¹²⁶ See Articles 25 of the FDRE and Oromia Regional Constitutions

¹²⁷The constitution of FDRE states Fundamental Rights and Freedoms in chapter three. And these rights are divided in to two parts. Part one is about Human Rights that goes through Article 14 -28. Part two is about democratic rights (from Article 29 – 44)

To conclude, the two Constitutions are not legal documents to be appreciated and considered as a milestone in protecting and promoting human rights of children with disability. True that all the human rights provisions enshrined in the Constitutions also applies to children with disability too. However, in the existence of all obstacles that hinders children with disability in exercising their rights equally with other children without disability, some protective and affirmative measure to be taken by the government and other stake holders should have been provided within these Constitutions. Especially taking into account the debate that existed between scholars on whether or not international and regional instruments that are not proclaimed through Federal Negarit Gazeta could be invoked before courts of law.

3.3.2 Other Legislations, Policies and Action Plan at National level

As it has been stated above, Ethiopia has tried to take various measure towards formulating legislations and laws related to disability. The policies and plan of Actions are framed based on the guidelines provided under international level. Under this sub topic the efforts of the government in protecting the rights of children with ID will be discussed in a general, without going through each of the legislations, policies and Action Plans.

- The Civil Code of Ethiopia prohibits a person with ID from entering in to a juridical act. Though the provision is to the interest of persons with ID since it protects them from fraud and deceitful acts, the term it uses to refer ID is so derogatory. It says ‘feeble minded’, in order to refer to ID. This is what the researcher finds to be humiliating and in need of amendment in accordance with the current development related with naming.
- The Revised Family Code of Ethiopia is also short of giving a special protection for children with ID. For instance, provisions that prohibits divorce because of delivery of a child with ID or at least a provision that imposes extra obligation up on a party who claimed for divorce because of this reason, prohibition of disowning because of this disability, especial protection of children with ID during divorce, etc.
- The Developmental Social Welfare Policy: reference to the inclusion, participation and independence of Persons with Disabilities, including children. Implementation strategies

include creating accessible physical environments, promoting positive attitudes towards disability, and assisting NGOs working on the issues.

- The National Plan of Action for the inclusion of persons with disabilities 2012-2021 is an ambitious policy framework that aims to mainstream disability issues in all fields of society. It makes provision for comprehensive rehabilitation service, equal opportunity in education for persons with disability, skills training and work, as well as full participation in the lives of their families, communities and the nation.
- The two Growth and Transformation Plans (GTP I and GTP II) identifies disability as a cross-cutting development issue. GTP I is the first poverty reduction strategy to mention disability explicitly.¹²⁸

3.3.3 Oromia Region Plan of Action on Persons with Disability

This plan of Action was prepared on 2016 in Afan Oromo language. It is classified under four parts. The first part is an introduction which comprises of the meaning of disability and core international and regional instruments to which Ethiopia is a party. The second part provides basic directions on the plan of action, the objective, and works and sectors for which priority will be provided. Different mechanisms applied and procedures followed by the stakeholders are provided under part three. The last part is all about budget allocation.

As it has been stated above some basic directions through which issues of disability are administered are included within the document. The plan of action provides that the directions are prepared based on the United Nations CRPD. It further stated that the directions are provided for, to strength the full participation and equal opportunity of persons with disability.¹²⁹ The basic directions include:

- Respecting the rights and capacity of children with disability;
- Avoiding discrimination;
- Full participation of persons with disability on issues that concerns them;

¹²⁸Sida, Disability Rights in Ethiopia, www.handicap-international.US/Ethiopia accessed at 16/5/2018.

¹²⁹ See Plan of Action on Persons with Disability of the Workers and Social Affair of Oromia Region, 2016, p 22

- Tolerating difference and widening the place that persons with disability have in the community;
- Equal opportunity;
- Accessibility and
- Equality between men and women.¹³⁰

The objective of the plan is to attain the equal enjoyment of rights of persons with disability with other segments of the society without disability; and realizing equality in education, health, accessibility of social services, training and employment opportunity, regardless of their age, sex, types of disability and the status of the family in the community.¹³¹

The plan also comprises of strategies to be followed in trying to achieve the above stated objective. The first strategy points out that there are two means to this end. The first means is accessibility of regional development programs which includes regular schools, health and transport services; and high ways. Whereas the second means is providing various services which is dependent upon the type of disability and the special need of persons with disability and their families. This includes social rehabilitation programs, orthopedics center, special need schools, etc.

The second strategy is *collaboration*. As it has been stated in the plan the government is not the only responsible organ for the achievement of the objective. Rather it needs the collaboration of NGOs and the society. As a third strategy, the full participation of persons with disability and their association on issues that concerns them is provided within the Action Plan. The fourth strategy is about children with disability. It states that the mental development of children with disability shall be worked on.¹³²

Different works that shall be provided with priority are listed within the action plan. The works that are given priority are ten in number; and these are:

- Awareness creation,

¹³⁰ Ibid

¹³¹ Ibid, p 23

¹³² Ibid, PP 24-25

- Health and health services,
- Persons with disability and HIV/AIDS,
- Education and training,
- Hiring and employment,
- Social security,
- Place of residence, buildings and roads,
- Cultural life, sport and recreation,
- Full participation of women with disability and
- Representation through associations of persons with disability.¹³³

Having said this much about the documents, now the researcher will show how some rights are protected under the above stated documents which includes international human rights documents, regional human rights documents, FDRE documents or regional laws and policies. The selected rights are:

- The right to family life
- The right to social inclusion/ the right to live in the community
- The right to education,
- The right to participate in play, recreation, and leisure,
- The right to best possible health,
- The right to an adequate standard of living/ protection from poverty,
- The right to be protected from all forms of violence and abuse.

3.4 The Right to Family Life

The family is usually the ideal environment for a child to grow up in, and it plays a vital role in ensuring the wellbeing of children. When a child is removed from its protective care, or the family is weakened or undermined in its capacity to provide that care, the cost for children is high. To date, too little attention has been given to introducing measures to ensure that the right

¹³³ Ibid, pp 25-34

to family life is upheld for children with disabilities, or to providing the support that families need to ensure these children's protection. In many societies, prejudice, ignorance and discrimination, combined with a lack of community-based support or social security provisions, undermine families' capacities to provide appropriate care and protection for a child with a disability.¹³⁴

The right to family life is the right of all individuals to have their established family life respected, and to have and maintain family relationships. This right is recognized in a variety of international human rights instruments, including Article 16 of the UDHR, and Article 23 of the CCPR. Hence, a child shall not be separated from his or her parents *against their will*, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child.¹³⁵ Such determination may be necessary in a particular case such as one involving abuse or neglect of the child by the parents, or one where the parents are living separately and a decision must be made as to the child's place of residence.

Here one thing that the researcher wants to emphasize on is the phrase '*against their will*', which refers to the will of the parents. According to this provision the best interest of the child will only be taken in to consideration while the separation is done against the parents will. It seems that in all other cases where the parents are willing to abandon their child they can do so. However, the same Convention also stipulates that States Parties shall use their best efforts to ensure recognition of the principle that both parents have common responsibilities for the upbringing and development of the child. Parents or, as the case may be, legal guardians, have the primary responsibility for the upbringing and development of the child; and the best interests of the child will be their baseline for measurement.¹³⁶ Thus, since the primary responsibility rests upon the parent or guardians of the child as the case may be, they cannot abandon their child on any ground, including disability, except when the best interest of the child requests so.

¹³⁴ Supra note 96, p 91

¹³⁵ See article 9/1 of CRC, similar provisions on the right to family life is set out under Articles 23/4 of CRPD and 19/2 of ACRWC

¹³⁶ See article 18/1 of CRC

The law being the one stated above, study shows that the stigma associated with disability can lead to children being hidden within the home, their existence denied and opportunities for the realization of their rights extremely limited.¹³⁷ It also contributes to the disproportionate number of children with disabilities being brought up in single-parent households – with fathers often abandoning the family when a child is born with impairment, leaving the mother to cope alone.¹³⁸ In some societies, the extended family will also withdraw support, further isolating the mother and undermining her capacity to provide adequate care for the child.¹³⁹

By emphasizing equal rights with respect to family life, the CRPD makes it clear that it is not acceptable to place a lower priority on the protection of family life for children with disabilities. The importance of family is the same for every child, irrespective of disability. In this regard, it is not adding any new principle or obligation to the CRC. However, it does spell out that the principle of nondiscrimination extends to family life for children with disabilities, and reaffirms the obligation to respect this right.

In its preamble, the CRC emphatically endorses the family as the natural environment for children, and recognizes the need for children to grow up within a family in “an atmosphere of happiness, love and understanding”. It emphasizes that families should be provided with all the necessary protection and assistance to enable them to fulfill their responsibilities. In support of this recognition, it includes a number of provisions that reinforce the right of children to family life. All the rights in the CRC apply to all children without discrimination on any grounds, including disability. These provisions therefore apply to children with disabilities on an equal basis with all other children. They place obligations on governments to provide support for parents to strengthen their capacities to care for their children. The General Comment on children with disabilities emphasizes that children are best cared for within their families, and to enable families to provide effectively for children with disabilities.

The CRPD introduces specific provisions which take account of the nature of rights violations experienced by children in relation to family life, and it places additional obligations on

¹³⁷

¹³⁸ Ibid, Pp 91-92

¹³⁹ Ibid, p-92

governments to take the necessary action to address these rights violations. Although rights with respect to family life apply to every child on the same basis, the nature of support needed to protect that right will differ according to the individual child. The CRPD recognizes that children with disabilities are often abandoned, concealed or neglected because parents do not understand the nature or causes of disability, or lack the knowledge, skills or capacity to provide the care the child needs. Accordingly, it introduces new obligations to provide families with “early and comprehensive information, services and support”:¹⁴⁰

- The emphasis on **early provision** is important. The sooner a disability is recognized or diagnosed, the sooner the child can start receiving the help she or he needs. For example, the development of a child with ID will be impeded if no one recognizes that she or he is with ID. The child will lose out, for example, on communication, socializing, forming friendships, play and learning.¹⁴¹

- Parents need **information** about the causes and nature of the impairment, whether there is any treatment necessary, and how to help the child accommodate or compensate for the impairment. In the case of the deaf child, for example, family members and the child need early provision of help with learning signing in order to facilitate communication. Information is vital to help the parent understand how to provide the best possible care for their child, and to recognize both the potential of the child and how to help them realize it. Many parents lack the skills, knowledge and resources to interact effectively with schools and healthcare services, while on the part of those services, too, there is often a lack of commitment to reach out to parents. Schools can organize meetings of parents to share with them information about how they are teaching the child, and updates on the child’s progress in order to help the parent to understand the child’s education. Many schools argue that this type of investment in parents is of equal importance to the education of children with disabilities as the direct learning the children receive in school.¹⁴²

- Parents also need to be **aware of their child’s rights** –Children with disabilities have the right to express their views and have them taken seriously, including within the family. They also have the right to be involved in decisions that affect them and to take responsibility for decisions

¹⁴⁰ See Article 23/3 of CRPD

¹⁴¹ Supra note 96, P 95

¹⁴² Ibid

they are competent to make for themselves. Parents and other care givers of children with disabilities can often be over-protective, and fail to make space for their children to acquire skills, become more independent and learn to manage risks. Parents need to be supported and encouraged to ensure that all these rights are respected. They also have a responsibility to advocate for their child's rights when they are not being fulfilled by governments and others. This may involve, for example, challenging a school's refusal to admit a child with a disability, or a failure to provide mobility aids or devices, or the failure to adapt public buildings to make them accessible.¹⁴³

- Parents need **services**, such as different forms of respite care, care assistance in the home, community-based daycare facilities, mobility devices, adaptations to the home, appropriately designed furniture, as well as help with laundry and consumable supplies.¹⁴⁴

Related to institutionalization, the CRC does not make any explicit reference to it for children with disabilities or to the need for alternatives, although the General Comment makes it clear that the Committee on the Rights of the Child is concerned about the continued use of institutions as a placement option for children with disabilities in many countries. The Committee recognizes that, in general, institutions provide a much inferior quality of care and render children more vulnerable to violence and abuse.¹⁴⁵ It recommends that they should only be used as a measure of last resort, when it is absolutely necessary and in the best interests of the child.¹⁴⁶ It further recommends that existing institutions should be transformed, with a focus on smaller facilities organized around the rights and needs of the child, that national standards should be introduced, and that there should be rigorous screening and monitoring procedures to ensure effective implementation of these standards.¹⁴⁷

The CRPD strengthens the shift from institutional care by recognizing the right of people with disabilities, including children, to live in the community, backed up with the necessary support and community-based services to make that possible. It requires governments to make every

¹⁴³ Ibid

¹⁴⁴ ibid

¹⁴⁵ Supra note 91, CRC/C/ GC 9, Para. 47

¹⁴⁶ Ibid

¹⁴⁷ Ibid

effort to ensure that when a family cannot care for a child, the alternative placement is either with the wider family or in a family setting in the community.¹⁴⁸ Placing children in institutions involves removing them from public view and effectively rendering them invisible. It is an approach which identifies the child as a ‘problem’ to be got rid of. The philosophy underpinning the CRPD encourages the removal of the social, physical, cultural, attitudinal and economic barriers that impede the realization of rights – not the removal of the child.¹⁴⁹

The CRC stresses where removal is being considered, children themselves should be consulted and their views taken seriously, in accordance with their age and maturity. The CRPD contains an additional key requirement that a child must never be separated from parents on the basis of disability.¹⁵⁰ This means, for example, that doctors, social workers, other professionals or the courts must never impose a decision to place a child away from parents simply because the child is with disability. Nor must they pressurize parents to agree to such a decision. The emphasis must be on providing for the child’s needs within rather than away from the family. Both the CRC and the CRPD require that the best interests of the child must always be the paramount consideration. The forced institutionalization of children with disabilities represents a form of discrimination. It would not be acceptable to deny the liberty of other children on this basis. Article 14 of the CRPD introduces a requirement on governments to ensure that people with disabilities, including children, are entitled to enjoy the right to liberty on the same basis as others. It also requires that any deprivation of liberty must be neither unlawful nor arbitrary and that the existence of a disability must never be used to justify the deprivation of liberty.

3.5 The Right to Social Inclusion/the Right to Live in the Community

Children with disabilities experience social exclusion in all areas of their lives. Physical barriers are part of the problem, as well as lack of accessible public transport or public space, resulting in children with disabilities being unable to participate in the activities enjoyed by other children. These difficulties are compounded by the attitudinal barriers faced by children with disabilities.

¹⁴⁸ See Article 23/5 of CRPD

¹⁴⁹ Supra note 96, P 96

¹⁵⁰ See Article 23/4 of CRPD

They are often shunned by their peers, marginalized from social and play activities, and physically and psychologically bullied.¹⁵¹ In consequence, it is common for children with disabilities to spend considerable parts of their childhood in isolation from all the usual activities associated with childhood.

Article 23 of the CRC establishes the right of children with disabilities to be able to enjoy a “full and decent life in conditions that ensure [their] dignity, promote self-reliance and facilitate the child’s active participation in society.” It also requires education, health, rehabilitation, recreation and employment services to be provided for children with disabilities to enable them to achieve the fullest possible social integration. The CRPD establishes as a general principle that children with disabilities are entitled to full and effective participation and inclusion in society.¹⁵² In order for this to happen, it is necessary to remove the many barriers that impede that participation.

The CRPD recognizes that lack of understanding about the nature of disability, together with negative stereotypes and prejudices, serve to marginalize children with disabilities from active participation in society. Accordingly, it introduces detailed obligations on governments to take action to challenge those attitudes, and promote respect for, and positive images of, people with disabilities, including:

- Public awareness campaigns to encourage receptiveness, and increase social awareness of the potential and abilities of people with disabilities
- fostering an attitude of respect for the rights of people with disabilities at all levels of the education system
- encouraging the media to promote positive images of people with disabilities
- developing awareness training programs on the rights of people with disabilities.¹⁵³

Language plays an important role in reinforcing or challenging negative stereotypes of disability. People with disabilities have struggled for many years to challenge terms that are degrading and

¹⁵¹ Supra note 96, P 99

¹⁵² See Article of 19 of CRPD, Similar provision on the right to live in the community is provided under Article 10 of the draft protocol on disability in Africa.

¹⁵³ See Article 9 of CRPD

insulting. It is important that governments, the media and others in positions of power as well as individuals in their day-to-day relations are encouraged to use language that is acceptable to people with disabilities.

Much of the isolation and exclusion experienced by children with disabilities is a result of lack of accessible information, interpretation and assistance. Without this provision, many children with disabilities cannot communicate with or engage fully with the external world. Accordingly, the CRPD requires governments to ensure access, on an equal basis with others, to information, communications and other services, including electronic services and emergency services. Children with disabilities need support to enable them to achieve and maintain maximum independence and full participation and inclusion in all aspects of life. Lack of training, services and facilities contributes to social isolation and dependency. The CRC stresses that assistance must be designed to ensure that children with disabilities have effective access to education, training, healthcare services, rehabilitation services, preparation for employment and recreation opportunities.

All these services should aim to ensure that they achieve the fullest possible social integration and individual development. The CRPD introduces more specific obligations on governments to develop habilitation and rehabilitation services and programs, particularly in the fields of health, education and social services, which are:

- provided at the earliest possible stage, multidisciplinary and based on individual needs and strengths
- provided as closely as possible to the communities in which children with disabilities live
- designed to support participation and inclusion in the community and in all aspects of society.¹⁵⁴

The CRPD Committee notes the importance of the “evolving capacity” of children – something that develops over time with the proper support. For children to develop the emotional and cognitive abilities to take full advantage of the right to live independently in the community, family protection is essential from an early age and continuing through adolescence. Thus, the

¹⁵⁴ Supra note 96, p 105

core element of living in the community for children is not just the protection from institutionalization but the affirmative support for living with a family. Many other living arrangements may exist in the community, such as group homes, small institutions, or so-called “family-like” institutions. But the scientific literature powerfully demonstrates that these are no substitute for the essential need of all children to grow up with a family.¹⁵⁵

CRPD provides stronger protection than CRC. At the time that the Convention on the Rights of the Child (CRC) was drafted, it was assumed that some children with disabilities needed to be in institutions. Thus, article 20 of the CRC states that when children are unable to live with their parents, they may be placed in “suitable institutions.”¹⁵⁶ CRC Article 23 implicitly recognizes this limitation when it calls for governments to provide services “conducive to” a child’s with disability “fullest possible social integration” – leaving open the idea that complete integration might not be possible for some children with disabilities. The CRPD moves away from a medical model approach that just promises services in the community and instead guarantees the outcome the right to live and be included in the community. And to implement this right, the CRPD Committee has made clear in other parts of this general comment there is no need for any person to be placed in an institution because of a disability.¹⁵⁷

3.6 The Right to Education

A general right to education was directly and specifically articulated for the first time in the UDHR. And it has been stated that:

¹⁵⁵Disability Rights International, Comments and suggested revisions to the UN Committee on the Rights of Persons with Disabilities Draft General Comment No. 5 On the right of people with disabilities to live independently, Washington, DC , June 30, 2017, p- 2

¹⁵⁶ The CRC was drafted during the 1980s, when the issue of institutionalization was not perceived as one of the most serious concerns. The then-Communist countries of Eastern and Central Europe, where institutional placement of children was part of the ideology governing child-protection systems, were among its active drafters. Therefore, it is understandable that an elastic definition of ‘suitable institutions’ might have represented the lowest common denominator in that geopolitical situation....**Today, more than two decades after the adoption of the CRC, it is appropriate to raise the question of whether institutional care can be a “suitable option” for children at all, especially for children under three years of age; whether any exceptions are acceptable; and whether it is time to seriously consider its elimination.**” United Nations Office of the High Commissioner on Human Rights, Regional Office for Europe, *The Rights of Vulnerable Children Under the Age of Three: Ending their Placement in Institutional Care*, 10-11 (2011)

¹⁵⁷ Committee on the Rights of the persons with disability, General Comment No. 18 on Article 19: living independently and being included in the Community, CRPD/C/18/1, 2017, Para. 58

‘Everyone has the right to education. Education shall be free, at least in the elementary and fundamental stages. Elementary education shall be compulsory. Technical and professional education shall be made generally available and higher education shall be equally accessible to all on the basis of merit’¹⁵⁸

The CRPD elaborates these rights in more detail. Firstly, it reaffirms the absolute right of children with disabilities to education without discrimination and on the basis of equality of opportunity. It also requires that governments take note of the following:

- Disability must never be a basis for excluding a child from primary or secondary education. The current practice in some countries, for example, of categorizing some groups of children as ‘uneducable’ is prohibited.
- Children with disabilities must be able to access inclusive, quality primary and secondary education on an equal basis with others in the communities where they live.¹⁵⁹

This provision requires that children with disabilities are able to go to their local schools in the same way that other children do. In order to ensure that this right is fully implemented, it is imperative that responsibility for the education of children with disabilities lies with the Ministry of Education, on the same basis and with the same rights as all other children. It must not remain, as too often happens, with ministries of social welfare. The barriers to education for children with disabilities exist at a number of levels, all of which must be addressed if the right to education is to be achieved.

The CRPD introduces specific obligations to ensure that these provisions are implemented, and that children with disabilities get access to education. These obligations are:

- Early identification and assessment of children
- Legislation that affirms the right of children with disabilities to education on an equal basis with others

¹⁵⁸ See Article 24 of the UDHR, Similar provision on the right to education is stipulated under Articles 13 and 14 of CESCR, Article 11 of the ACRWC and Article 12 of the draft Protocol on disability in Africa.

¹⁵⁹ See Article 25/2 of CRPD

- Schools to make ‘reasonable accommodation’ so that schools are physically accessible for all children
- Provision of accessible transport to school
- Provision of the necessary aids and adaptations to enable all children to learn on an equal basis
- Flexibility in the curriculum and the teaching methods
- Awareness-raising of teachers, parents, religious and community leaders to enhance understanding of disability and the rights of children
- Provision of effective individualized support measures to maximize children’s academic and social development, including: – enabling children to learn Braille, alternative script, augmentative and alternative modes, means and formats of communication, orientation and mobility skills – enabling children with hearing impairments to learn sign language and promote the linguistic identity of the deaf community – ensuring that the education of blind, deaf and deaf-blind children is delivered in the most appropriate language and means of communication
- Training and employment of teachers qualified to work in inclusive environments, and, where necessary, in sign language and/or Braille.¹⁶⁰

It is not sufficient that children with disabilities have access to education. *It must also be inclusive.* The UN made a clear commitment to promoting inclusive education as early as 1994 in the Salamanca Statement, which called on governments to “adopt as a matter of law or policy the principle of inclusive education, enrolling all children in regular schools, unless there are compelling reasons for doing otherwise”.¹⁶¹ UNESCO, as the lead UN agency on education, provides the following definition of inclusion: “Inclusion is seen as a process of addressing and responding to the diversity of needs of all learners through increasing participation in learning, cultures and communities, and reducing exclusion within and from education. It involves changes and modifications in content, approaches, structures and strategies, with a common vision which covers all children of the appropriate age range and a conviction that it is the responsibility of the regular system to educate all children... Inclusion is concerned with the identification and removal of barriers...”¹⁶²

¹⁶⁰ See Article 25 of CRPD

¹⁶¹The Salamanca Statement and Framework for Action on Special Needs Education, Adopted by World Conference on special needs education, Access and Quality, Salamanca, Spain 7-10 June 1994, Para. 3.

¹⁶² UNESCO, Guidelines for Inclusion, Ensuring access to education for all, UNESCO, 2005, PP 13-15

The CRC does not specifically demand inclusive education, although, as noted above, it does insist on the right to an education on the basis of equality of opportunity and on education designed to achieve the child's fullest possible social integration. The Committee on the Rights of the Child, however, stresses that inclusive education should be the goal of educating children with disabilities, and it encourages all governments to begin a program that aims to achieve inclusive education.¹⁶³

The CRPD goes further and insists on an inclusive education system at all levels. It is important to stress that simply placing excluded children within a mainstream setting does not of itself achieve inclusion. This can only be achieved by addressing all aspects of the education system, including the curriculum, teaching methods, school culture and the school environment. All levels of the system must be adapted to ensure that the system adapts to the child, rather than expecting the child to adapt to the system.¹⁶⁴

Thus, children with ID have as equal right to education as their peers without ID. Further, article 2 clearly describes this fact by stating "*everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, color, sex, language, religion, political or other opinion, national or social origin, property, birth or other status*". In this provision, it is possible to include children with ID in the protection by interpreting the phrase "*other status*".

3.7 Right to Participate in Play, Recreation, and Leisure

It is probably in the field of play, recreation and leisure activities that children with disabilities, including children with ID, experience the most acute sense of social exclusion and marginalization. Consultations with children repeatedly reveal the importance that they all attach to their relationships with their peers.¹⁶⁵ Children with disabilities are no different. They, too,

¹⁶³ Supra note 91, CRC/GC No. 9, Para. 66

¹⁶⁴ Ibid

¹⁶⁵ Supra note 96, p 117

want opportunities to be with friends, to play, to have fun, to ‘hang out’. However, for them, physical, attitudinal, cultural and social factors can place almost insuperable barriers in the way of the daily activities that other children are able to take for granted. Play is also at the core of children’s physical, cognitive, social, moral and emotional development. It is invaluable for exercising creativity, as protection for working children, as a therapeutic tool and as a means of celebrating cultures and communities. Accordingly, exclusion from play represents a major exclusion from life for children with disabilities. Article 31 of the CRC¹⁶⁶ highlights three dimensions of the right to play that need to be addressed in respect of children with disabilities:

- **Opportunity for play and recreation** – It recognizes the right to play, leisure and recreation, and also requires governments to encourage the provision of appropriate and equal opportunities for recreational and leisure activity. The specific reference to equal opportunities, taken in conjunction with Article 2, the right to non-discrimination, clearly states that provision must be encouraged for every child, including children with disabilities.¹⁶⁷

- **Play appropriate to the age of the child** – the Committee on the Rights of the Child interprets this provision as including the mental and psychological capabilities of the child as well as his or her chronological age.¹⁶⁸ This means that the importance of opportunities for play which is appropriate for children with different aptitudes, capacities and interests must be recognized.

- **Inclusive play** – the Committee on the Rights of the Child has emphasized that opportunities for children with disabilities to play with and alongside non-disabled children is a vital building block towards developing an inclusive society.¹⁶⁹ The CRPD, a document that builds on the CRC, imposes a specific obligation on governments to take appropriate measures to ensure that children with disabilities have equal access with other children to participation in play, recreation and leisure, including those activities within the school system.¹⁷⁰ This obligation must not be

¹⁶⁶ CRC, Article 31/1 ‘States Parties recognize the right of the child to rest and leisure, to engage in play and recreational activities appropriate to the age of the child and to participate freely in cultural life and the arts.’ This right is also recognized under Articles, 15 of CESC, 12 OF ACRWC, and 20 of the draft Protocol on Disability in Africa.

¹⁶⁷ Supra note 96, p 118

¹⁶⁸ Supra note 91, CRC/C/GC No. 9, Para. 70

¹⁶⁹ Ibid

¹⁷⁰ See Article 30 of CRPD

understood as being limited to the provision of parallel opportunities that are equal but separate. Rather, it clearly implies the right to equal and inclusive opportunities for play.

Finally, the CRPD stresses that there must be, on an equal basis with others, recognition of and support for the specific cultural and linguistic identity of children with disabilities, such as sign languages and deaf culture.¹⁷¹

3.8 The Right to Best Possible Health

Many children with disabilities find that healthcare facilities, including dentists' and doctors' surgeries, and clinics, are physically inaccessible to them, and that health professionals do not understand their condition and cannot communicate with them, or they treat them with indifference or contempt.¹⁷² These children are often unable to reach healthcare facilities, owing to lack of accessible transport. Services to address their specific needs are also often lacking. In consequence, they experience inadequate healthcare, and certainly a lower quality of service than non-disabled children.¹⁷³

Children with disabilities experience widespread disregard for their views when decisions related to their healthcare are being made. They are often overprotected by their parents, who underestimate their capacities and make decisions on their behalf. Similarly, health professionals often fail to involve children with disabilities, not providing them with information and opportunities to ask questions, and displaying a lack of interest in or respect for their views. Yet, in practice, many children with disabilities, who may have significantly more experience of medical interventions than other children of comparable ages, are likely to have greater understanding of their condition, and to have acquired greater capacity for informed decision-making.¹⁷⁴

¹⁷¹ See Article 30/4 of CRPD

¹⁷² *Supra* note 96, p 121

¹⁷³ *Ibid*

¹⁷⁴ *Ibid*

The right of every child to optimum development and to the best possible health, without discrimination, is explicitly established in the CRC and ACRWC. It is also reaffirmed in the CRPD and the draft Protocol. While CRC and ACRWC introduces a number of specific obligations on the part of governments to ensure the realization of the right to the best possible health, the CRPD and the draft Protocol complements these two documents with additional provisions which address the particular difficulties faced by children with disabilities in achieving access to healthcare.

The CRPD places an obligation on governments to ensure not only those children with disabilities can access health services, but also that they are provided with the same range, quality and standard of healthcare and health programs as others.¹⁷⁵ It also requires health professionals to provide the same quality of care.¹⁷⁶ This means that action must be taken to ensure that all health facilities and equipment are accessible. In addition, health professionals will need training in the treatment of children with different disabilities, and interpreting should be provided where necessary.

Health professionals need to be provided with training to raise their awareness of these rights and to help them involve children in decision-making. Children with disabilities may require some health services specifically because of their disabilities. They need, for example, early identification and intervention to ensure that any impairment is diagnosed at the earliest possible stage and that appropriate services are provided. Article 25(b) of the CRPD places an obligation on governments to ensure that the specific health services required by children with disabilities are provided. Paragraph (c) also requires that these services be located as closely as possible to children's own communities. Local services are of particular importance to children with disabilities, because of both poverty and the practical difficulties they face in accessing transport. These provisions are consistent with the obligation in both Conventions to ensure that children with disabilities achieve the highest possible standard of health, and with Article 6 of the CRC, which stipulates that governments must ensure the development of the child to the maximum extent possible.

¹⁷⁵ See article 25/a of CRPD

¹⁷⁶ See Article 25 of CRPD

3.9 The Right to an Adequate Standard of Living

Disability is both a cause and an indirect consequence of poverty. Poor children are more likely to be malnourished and experience vitamin A and iodine deficiencies, more vulnerable to infection, and less likely to have resistance to illness or access to health care. They are more likely to lack clean water and sanitation, and are more exposed to accidents. For example, in some rural communities, children are often left alone to care for younger children, in huts with open fires in the center.¹⁷⁷

This exposes small children to a high risk of burns and accidents. In some communities, children are deliberately disabled in order to ‘enhance’ their effectiveness as beggars. Children, who work illegally, or in hazardous occupations, are at very high risk of exposure to injuries and illness resulting in disability including burns, eye and hearing impairments, loss of body parts and respiratory and gastrointestinal illnesses.¹⁷⁸ Once a child has a disability, their mother is commonly abandoned, leaving her alone with the child. Evidence from all over the world indicates that where a family has a child with a disability, it is more likely to be headed by a single parent. The mother then faces a triple jeopardy. She cannot work easily with a disabled child to care for, the child’s condition may necessitate extra expenditure, and the father, often the major breadwinner, is no longer there. In other words, she carries an increased burden of costs, while her productive capacity diminishes. In consequence, families with children with disabilities are disproportionately represented among the poorest in most societies. The difficulties are further compounded by the endemic failure in most developing countries to ensure the right of access to education for children with disabilities. This condemns them to a future life in which they lack the knowledge, skills and opportunities with which to rise out of poverty.¹⁷⁹

Article 26 of the CRC recognizes the right of children to benefit from social security provisions that take account of the circumstances of the child. Article 27 establishes the right of every child to a standard of living adequate for their proper development, and emphasizes that parents have

¹⁷⁷ Supra note 96, p 125

¹⁷⁸ *ibid*

¹⁷⁹ *Ibid*

the primary responsibility to provide for their children.¹⁸⁰ However, it also places responsibility on governments to assist parents in fulfilling their child's right to an adequate standard of living, particularly where parents are poor.

Governments must provide social security, material assistance, and help with food, clothing and housing. Article 28 of the CRPD reaffirms the right to an adequate standard of living. It also stresses the need for continual improvement of living conditions, in recognition both of the prevailing conditions of poverty facing most children with disabilities and of the need for progressive realization of social and economic rights.

In advocating for an adequate standard of living for children with disabilities, it is important to draw on the provisions in both Conventions, as the CRC focuses on the particular issues facing children while the CRPD takes account of the specific circumstances of children with disabilities. Article 27 of the CRC demands more than the prevention of absolute poverty. It requires that children have access to a standard of living which will enable them to thrive and develop fully, and which is consistent with their human dignity. The wording of Article 27 recognizes that children's development is strongly influenced by their living conditions. It lists different components of development including mental, spiritual, moral and social as well as physical, thus acknowledging that the obligations of parents and governments to children extend beyond the basics of food, clothing and housing. Because the costs associated with disability may be higher than for other children, the CRPD recognizes that children with disabilities may need a larger income to enable them to develop adequately. Article 28, therefore, sets out more specific obligations to provide for children with disabilities.

Governments must:

- Provide services, devices and assistance to address all disability-related needs. These might include, for example, extra laundry services, adaptations to the home, or additional

¹⁸⁰ The CESCR on Article 9 and 11, and the draft Protocol on Article 16 also recognizes the right to highest standard of living and social protection in a more or less the same wording.

care needs. The services must be affordable, and therefore should either be free of charge to all children with disabilities, or subsidized through a process of means testing.

- Ensure access to social protection and poverty reduction programs, in particular for women and girls. Specific social security provisions should be available to families with a child with a disability, in recognition of the additional costs associated with disability such as special food or diet, transport, extra heating, and wear and tear on clothing, and also of a parent's reduced opportunities to undertake paid employment when they are caring for a child with a disability. Social security benefits should also take into account the fact that many families with a disabled child are headed by a single parent, usually the mother, and there is no other breadwinner
- Provide assistance with other disability related expenses such as training, respite care and counseling. In addition, the CRPD requires that the steps taken by governments to safeguard and promote an adequate standard of living must not discriminate on grounds of disability. In other words, any social protection measures must be available to children with disabilities without discrimination.¹⁸¹

The CRC recognizes the right of children to be protected from economic exploitation and from any work which is likely to be harmful to their development in any way, or to interfere with their education. It requires that governments take legislative, administrative, social and educational measures to ensure that the necessary protection is provided, including a minimum age for work, regulations on the hours and conditions of work and adequate penalties to ensure that the law is enforced.

The CRC requires governments to introduce measures to enable a parent to claim maintenance from an absent parent in respect of any child for whom they are responsible. This is of particular importance, given the disproportionately high number of mothers who are caring alone for a child with a disability.

3.10. The Right to protection from all forms of Violence and Abuse

¹⁸¹ See Article 28 of CRPD

Children with disabilities face a disproportionate risk of both physical and sexual violence and abuse, with some studies indicating that they are up to five times more likely to face violence than their non-disabled peers.¹⁸² The causes are complex, but relate to widespread social attitudes of rejection and hostility to disability, lack of understanding as to the nature of disability, greater levels of dependency among children with disabilities, and the social isolation of children with disabilities. The violence is also linked to these children's reduced capacity to challenge or protect themselves and the consequent comparative immunity from prosecution enjoyed by the abusers. In addition, children with disabilities are vulnerable to medical and scientific interventions undertaken without their consent and often without regard to their best interests.

However, to date, very little action has been taken to tackle violence against children with disabilities. Very few governments currently address the need to develop child protection services that are accessible or appropriate for them. For example, 'hotlines' and 'keep safe' programs are largely irrelevant to many children with disabilities. They are less likely to have access to information about their rights, and therefore do not know what they are entitled to challenge. And even if they have that knowledge, there are few opportunities for reporting or challenging the abuse through accessible or effective complaints mechanisms.¹⁸³

Article 19 of the CRC requires governments to introduce legislative, administrative, social and educational measures to protect children, including children with disabilities, from all forms of violence while in the care of a parent or other legal guardian.¹⁸⁴ Article 16 of the CRPD also introduces obligations to take appropriate measures to prevent all forms of exploitation, violence and abuse.¹⁸⁵ As per the Convention, these measures need to be age and gender sensitive, taking account of the particular vulnerability of women and girls to violence and the need for targeted measures to address the situation of children. They also need to provide support for children with

¹⁸² Supra note 91, CRC/C/GC No. 9, Para. 42

¹⁸³ Supra note 96, P 128

¹⁸⁴ The right to be protected from all forms of violence and abuses is a right recognized under Article 7 of CCPR. The ACRWC under Article 16 also obliges state parties to take specific legislative, administrative, social and educational measures to protect the child from all forms of torture, inhuman or degrading treatment and especially physical or mental injury or abuse, neglect or maltreatment including sexual abuse, while in the care of the child.

¹⁸⁵ Similar provision is found under Article 5 of the Draft Protocol on disability in Africa.

disabilities and their families and caregivers, including information and education on how to avoid, recognize and report instances of exploitation, violence and abuse.

The General Comments of the Committee on the Rights of the Child, both on children with disabilities and on protection from violence, provide more detailed examples of preventive measures which need to be implemented, including action to:

- Introduce legislation prohibiting all forms of violence, including corporal punishment in all settings, including the home, family, schools, institutions and the juvenile justice system
- Promote public awareness of positive, nonviolent forms of parenting and education
- Train and educate parents or others caring for the child to understand the risks and detect the signs of abuse of the child
- Ensure that parents are vigilant about choosing caregivers and facilities for their children, and improve their ability to detect abuse,
- provide and encourage support groups for parents, siblings and others taking care of the child to assist them in caring for their children and coping with their disabilities
- Ensure that children and caregivers know that the child is entitled as a matter of right to be treated with dignity and respect and they have the right to complain to appropriate authorities if those rights are breached
- Ensure that schools take all measures to combat school bullying and pay particular attention to children with disabilities, providing them with the necessary protection while maintaining their inclusion in the mainstream education system
- Ensure that institutions providing care for children with disabilities are staffed with
- Especially trained personnel who have been properly screened, according to appropriate/ standards, regularly monitored and evaluated, and that the personnel have access to sensitive complaint mechanisms.¹⁸⁶

¹⁸⁶Committee on the Rights of the Child, General Comment No. 8, ‘the rights of children to protection from corporal punishment and cruel or degrading treatment’, CRC/C/GC/8, 2007, Para. 2 and 37

Violence against children with disabilities often takes place within the very facilities and programs designed to protect and assist them.¹⁸⁷ Article 16(4) of the CRPD places an obligation on governments to ensure that all services for children with disabilities are effectively monitored. It is imperative that any monitoring systems are fully independent of the government, or the provider of the service, in order to ensure rigorous scrutiny and the power and authority to expose abuse of the rights of children with disabilities.

Conclusion

This chapter is entirely devoted to discussion of the selected rights recognized under the international, regional and national laws of the country. It begins with a brief discussion of major international and national legislations which includes, CRC, CRPD, ACRWC, Protocol to the ACHPR on the rights of persons with disability; FDRE and regional Constitutions, civil and revised family codes of Ethiopia. National and Oromia regional action plans and policies are also discussed under this chapter.

The main part of the chapter is the discussion on the seven selected rights under various international and national documents. The selected rights are the rights to family life, social inclusion/live in the community, education, participate in play, recreation, and leisure, best possible health, an adequate standard of living/ protection from poverty, to be protected from all forms of violence and abuse. Interpretations of the rights provided by different General Comments of various Committees are also cross referred. The selected rights are found to be attached to the day to day activities of children, including children with disabilities and rights most frequently violated by others. Hence the extent of recognition of such rights under various documents is assessed and explained so that the practice will be analyzed in the next chapter from the perspective of the norms.

¹⁸⁷ Supra note 96, p 132

Chapter Four: Implementation of Selected Rights of Children with Intellectual Disability in Ambo City

4.1 Data Presentation, Analysis and Interpretation

Some basic information about the participants of the study is provided hereunder. However, readers can see annex A at the back of this thesis for detailed information of all of the study participants.

Among the ten study participants seven of them live with their parents, 2 of them with their single mother and one participant with his grandparents. None of these children with ID have friends without their family members and also none of them were learning at the time the data is collected. Moreover, all of the study participants live under poverty and face violence in common.

Here before, directly going to the analysis of the data, the researcher will have some statements about the association that helped in collecting the data, VCBRA. The association was all part of the data collection process.

Vision Community Based Rehabilitation Association: -it is a local non-governmental organization established nine years ago by Ethiopians to provide support for persons with disability in general, and children with disability in particular. It provides different kinds of aid for all types of victims of disability according to their need. The founders were formerly working on government offices on special needs. The association is in most cases engaged in giving technical services than financial aid. It covers medical expenses of the child with disability, and above all it follows the status and progresses of its clients through the home to home service delivered by the social workers. It also has awareness creation programs for the clients and other community members. A couple of months ago before the data collection, some clients of the

association took 2,000 Ethiopian birr in the form of loan and started their own business.¹⁸⁸Hence, loan is also another service that the association provides.

At the time of its formation, getting clients was a little bit difficult.¹⁸⁹The association was conducting survey by going door to door and asking if there is any child with disability in that house. Hence, what hinders them was first, many people were not willing to disclose the existence of a child with disability in their house; second those families who were eager to get the service provided, steps backward when they know that there will not be any financial or material support to be given regularly. Therefore convincing the community through work that what VCBRA will be providing is beyond the financial aid that some people were expecting became the very first duty of the association. Side by side they also tried to gather information from neighbors on the existence and non-existence of a child with disability with the help of elderly persons. By now the association more or less seems to convince the community. Parents are expecting the social workers with bright face, since they saw an incredible change on their child after VCBRA's intervention. Hence, currently the screening is conducted mainly from the information gathered from the society and mostly based on the application of the clients themselves.

VCBRA is working on all kinds of disability. It has its own paid social workers. Each of them has at least 25 clients. They are all trained on the kinds of assistance they will be providing for their clients. All social workers are expected to visit five clients per day and shall visit one client twice per week in principle. However, the number of clients that VCBRA has is increasing this days and the load is on the social workers. For instance, one of the social workers has 42 clients; and it is practically impossible for a person to visit clients twice per week though one can visit five clients per day.¹⁹⁰

The service that is provided by the social workers at the home of their clients includes awareness creation, and the treatment that the family should extend to the child with disability. They also give a physiotherapy services for children who are in need. Furthermore, the social workers organize a coffee ceremony at the house of their client and invite the neighbors. Through such

¹⁸⁸ Interview with V2, an administrative and financial head at VCBRA, on June 12, 2018

¹⁸⁹ *ibid*

¹⁹⁰ Interview with V3, a social worker at VCBRA, on June 12, 2018

mechanisms, they try to raise the level of awareness of the community about disability and also try to solve the problems of the child with disability living in that house. This ceremony also helps gather information about other children who are not under the umbrella of the association.

One of the core challenges that it is facing is lack of capacity to reach all applicants who are in need of its help.¹⁹¹The scope of the association is Ambo city and Guder town. However, people are in most cases applying from different surrounding localities of the city. At this time, though it is out of the scope area, the association is trying to support them if it found the case to be critical, especially if the child with disability has to be taken to hospital immediately; it gives financial aid for such issues. But those families are not going to be considered as clients and no follow up services or any other kind of services provided for clients is also extended to them.

Here one has to bear in mind that VCBRA is not an association that is established to work on the human rights of children with ID. Principally its aim is to provide aid for persons with disability. But in the meantime though it doesn't monitor and advocate on issues of human rights of children with ID, it is getting involved on the practical implementation of those rights of children with ID. The awareness creation programs and the assistance made by the association positively add to the promotion and protection of human rights of children with ID.

Having said this much about VCBRA, the researcher will be assessing the implementation of the selected rights on the basis of the outline rights provided in the preceding chapter.

4.2 Right to Family Life

The assumption is that there is no place in the whole world like home, especially for children with disabilities. It is considered to be a safe haven, a place where the interests of the child is well respected and protected than any other places. But this is not an absolute fact since there are times where home becomes place of misery.

None of the study participants are institutionalized. However this does not mean that all parents are keeping their child with ID willingly. Rather some are doing so out of lack of other options in their locality. For the question of institutionalization option¹⁹² more than half of the informants replied positively. They would have left their child with ID in institutions, had they been

¹⁹¹ *ibid*

¹⁹² See Annex E, Guideline for interview with parents or Guardians of the child with ID, question No. 7

requested to do so. Especially one of the key informants said that she would do everything in her power if she gets the chance to leave her child with ID in an institution.¹⁹³ As a reason for this, all of the informants raised the fact of being confined at home to look after their child with ID. Out of all informant families half of them are earning a regular monthly income and the rest families earning is dependent upon the breadwinners getting job daily, since they are laborers, with no formal education and profession (the so called ‘Ken serategna’ in Amharic.) Hence, all parents and guardians who preferred institutions, tried to justify their decision, saying that it is beyond their financial capacity to hire a nanny for their child with ID and go to work. One of the informant parents stated that it would definitely be to the advantage of her child with ID, if she gets an institution which will be taking care of her child than being tied with a rope.¹⁹⁴

One of the family members of a child with ID dropped out of school to look after her nephew with ID.¹⁹⁵ She said that the Childs’ parents want to hire a nanny. But it is hardly possible for them to get one, since his care needs more effort and attention than other children of his age without ID. Nannies that are in most cases coming from countryside of Ethiopia have got a negative perception towards children with ID, as they are parts of the whole community. They do have a fear of coming closer to the child, as if he is a victim of communicable diseases. Be it as it may, the parents are not willing to leave their child with ID in an institutions.

Out of the three informants who said that they will not leave their child with ID in an institution, P4 is the only person who accepted his child with ID as he is and puts no reservation on his decision to keep his child with him. He seems so passionate on this issue and talks with full confidence. As it has been inferred from his expression this is somewhat related with his religion.¹⁹⁶ He believes that his son is a gift from Allah, and it is his duty to care for the upbringing of the child.

¹⁹³Interview with p1, mother of a child with ID, on June 08, 2018. C1 is named after her grandfather since her parents had already divorced because of her disability.

¹⁹⁴ See photo 8 at page 71 of this research paper.

¹⁹⁵ Interview with F1, on June 08, 2018

¹⁹⁶ Most families without changing their internal perception about the disability try to pretend that they are changed. Because they assume that this is what VCBRA is expecting from them. They pretend that what has been told by the social workers is accepted in its entirety. This is partly a problem that comes from the way the social workers approach their clients. The researcher witnessed one social worker warning her client not to link the disability with spiritual issues than trying to convince the client based on logic as a professional. The researcher believes that such kind of awareness creation will only create fear of an order given by a superior. Especially when it comes to this case where most of the clients are illiterate and poor the clients might fear that the association might stop its aid if

From this what the researcher concludes is that though much of such decision is dependent upon the financial capacity of the parents, since those who are capable of hiring nannies are not also in a position to get one, the problem cannot only be averted by strengthening the financial capacity of the families. Much has to be done on changing the attitude of the community at large.

Institutionalization, which should be the last resort as per the general comments on the child with disability, is not the only measurement of whether the right to family life is violated or not. However, if the family keeps the child, but discriminates, hides and/or mistreats him/her it still is violation of family life. Hence, the fact that a child with ID in a given family does not learn or play but other children of that family does, shows the existence of discrimination in the family. In addition to this parents confine their child with ID in a given place and prayers like wishing the death of a child with ID shows mistreatment.¹⁹⁷

None of the parents or guardians had recognized the existence of the disability at the time of pregnancy or while the child was infant. All of them figured out the existence of disability accidentally. For instance, parents of C1, C2 and 10, the study participant children with ID recognized the existence of disability while they took their children to hospital for other kind of treatments. Surprisingly, parents of C5 and C6, who are with ID, realized what their two children are facing is one kind of disability the moment VCBRA approached the family while conducting survey for screening purpose.

Such kind of story also goes to other families too. The problem related with a very late diagnosis of the disability is lack of the necessary treatment and care for the child at a time needed. One of the informants used to punish both of his children with ID believing that they are dull and fail in their lessons because of their stupidity. However, currently VCBRA seems to minimize the effects of such late recognition through awareness creation programs extended to the families and neighbors using a coffee ceremony to be held at the home of every client.¹⁹⁸

they do not accept orders. Hence, without changing their attitude deep inside, they may only pretend and repeat the statements of the social workers. Yet one has to bear in mind that this is not what VCBRA wants. Rather it is the result of the social workers misconception of the goal of VCBRA and their personal achievement towards it. Clients' attitudinal change is one measurement of the social workers achievement. That is why they are putting their own statements on the mouth of their clients.

¹⁹⁷ Interview with P1, on June 07.2018

¹⁹⁸ See page 50 Para. 2 of this thesis on the coffee ceremony to be held at clients house

Parents are getting prior information about the care that should be given to their child with ID from the trainings and awareness creation programs of VCBRA. It is apparent from their explanation that they also know what rights children with disabilities have. The main problem is with delivery of services. As it has been discussed in detail under chapter three of this thesis respite care, day-care services, help in laundry services, appropriately designed furniture, etc are expected to be provided to children with ID. This is considered to be the obligation of the government to fulfill. However, nothing yet has been provided from the government side. Rather VCBRA is trying its best in providing different furniture's like sitting, standing and walking frames to children with ID who are in need of it. Parents and guardians of children with ID are yet mentioning the problem related with nannies and day-care services as a main problem. Sanitation and laundry services are also another problem. There are children with ID who are needs of sanitation pads and dippers. But none of them are able to get. Some of them do not wear anything under their waist, and others were messed up with urine the time the data is collected.

It is only two of the study participants who are living with their single mothers. There is also a child living with their grandparents. The rest are living with both of their parents. Hence, it seems that probably the attitude of men related with disability and sharing of responsibility is by now a little bit changed. They know the detail status of their children and also are ready to support them. This is what the researcher had figured out while collecting data.

Finally, the researcher wants to emphasize that each model of care (institutionalization, family-based care, etc.) has its strengths and weaknesses, with primary goals being to provide a quality environment for children, opportunities for learning and growth, and protection from harm. Institutionalization is also considered to be the last resort for children as it has been mentioned under chapter three of this thesis. However, given the existing situation where none of the indicators of the right to family life exists, institutionalization of children with ID is the best option. Though it is claimed to be the last resort, the time of that last resort seems to arrive at this point. All the mistreatments, negligence, discrimination and poverty are problems faced by those children with ID. They are not enrolled in education, are confined and even tied up in a given place as an animal. Hence, the researcher believes that in the case at hand, institutionalization of a child with ID amounts to removal of the social, physical, cultural, attitudinal and economic barriers that impede the realization of this right, not removal of the child up until the above stated

barriers are removed. This is because of the practice that shows the existence of all the above stated barriers, though the children are yet living with their family.

Moreover, studies also shows the existence of long-term outcomes of children placed in institutional care having a more nuanced positive outcomes, particularly among children over age 5 and living in low-income countries.¹⁹⁹ For example, the Positive Outcomes for Orphans study conducted in Cambodia, Ethiopia, India, Kenya, and Tanzania has found that children living in institutional settings scored as well or better than their counterparts in family-based care across measures such as physical and emotional well-being.²⁰⁰ Hence, institutions would also possibly be the best option for children with ID.

4.3 The right to Social Inclusion/live in the Community

This right is one way or another related with other rights like the right to family life, education and health. The researcher believes that it is only a child whose right to family life is respected who will have a chance to live in the community. The same is true for the right to education since school is the perfect place for children to lead their social life and have friends to play with. Employment is also another opportunity for children of above 14 years to have a social life.²⁰¹

Six of the participant children with ID were confined in a given place, sitting alone, doing nothing and some of them crying out loudly the time the researcher went to visit them at separate occasion. The time the data is collected in a separate occasions, C2 was playing with his father and C1 was also sitting with her families while they were drinking coffee. Yet while C6 went to school though he was not allowed passing the main gate of the school and C8 was waiting for her step mother with her half-sister in front of her house. The C8 is only allowed to go out of the house if her step-mother has to leave to run her own business, like shopping. This is because the door has to be locked up until she comes back. The younger half-sister will be in charge of taking care of the child with ID until her mother comes back.²⁰² The half sister believes that the child with ID is incapable of taking care of herself. As a justification for the incapability she raised ‘mental illness by referring to her fathers’ statement.

¹⁹⁹National Academies Press (US), Forum on Investing in Young Children Globally, June 17 2016

²⁰⁰ Ibid

²⁰¹ See proclamation No. 377/2003.

²⁰² Interview with F3, half-sister of a child with ID, June 7, 2018



Photo 1: A child with ID and her half-sister

Children with ID can only live in the community where the attitude of the later about such disability is changed and cease to link it with evil spirit. Most of the family members and neighbors of these children believe that the disability is the result of the act of evil spirit. Parents of a child with ID refer to the falling down of their child around river and other places they believe it to be bad, at about 1:00 am.²⁰³The parents said that it is after the evil spirit attacked their child that the disability comes. It is only parents of one study participant and two neighbors of another child with ID who said that the disability is related with some biological disorder though it was difficult for them to explain it in detail. However C8s' parents yet think that it has something to do with spiritual case. This can be inferred from what C8 is wearing on her right hand ²⁰⁴(see the right hand of the child on the right, Photo 2 above)

Neighbors play an important role in the protection or violation of the right to live in the community of children with disability. In the case at hand, the perception of the neighbors on issues of violation of this right is more or less the same. They link the violation of this right to the acts of the families of the child with ID. Since the child with ID is not allowed to leave his/her home, the probability of having social life is less. Hence, to say that the neighbors act or attitude also accounts for such exclusion, the families shall first let the child freely live in the

²⁰³ The places and the time referred are traditionally considered by that community to be the place and time suitable for the evil spirit to attack people.

²⁰⁴What C8 is wearing is a sign of persons who are baptized by wholly water and are labeled to be with evil spirit according to the followers of Orthodox Christian religion.

community. Some neighbors claim that they are even ignorant of the existence of a child with ID in the neighborhood, except in case where their own family members' mentioned of the intricacy that the family having a child with ID in the neighborhood is living in.²⁰⁵ The mother of one participant child with ID used to sell sugarcane in her house which is near to school; and many of students who came to buy the sugarcane gave a bad look to her child and most of the time runs away if they found him in front of the gate. There are even times when children from the neighborhood and students of the nearby school merely came to see the child with ID as if he is a different creature. When they saw him they shout and run, and this makes him feel sad and cry. Therefore, the mother of the child with ID decided to stop selling sugarcane and also confined her child at home, to protect him from such kind of mistreatment.²⁰⁶ On the other handsome children by themselves do not want to have any relationship with children without ID. They have such a fear that other children might not be willing to come closer and have relationships with them too, or in extreme situations may abuse them.²⁰⁷

Related to this right, another important thing that the researcher wants to mention is the fact that people took advantage of children with such disability when they get the chance to do so. For instance, many people took advantage of children with ID by letting them work different types of works without payment or with a very little payment.²⁰⁸ The employers are doing this intentionally knowing that the child does not have the capacity to bargain with them.²⁰⁹

Additionally, school, as it has been stated above, is another important place for a child to build his/her social life. At the time of data collection none of the participant children with ID were learning. However, Awaro Elementary School had a special class²¹⁰ and there were 10 students with ID learning there. The only teacher of the special class stated that those students with ID had a good relationship with other students without ID. According to her, they play together at break time. However, the director of the school, said that they tried to limit the time students with ID meet with other students without ID, to protect the former from unnecessary abuse by the later. Students with ID were expected to arrive at school at 9:00 am in the morning shift; and

²⁰⁵Interview with N3, June 06, 2018

²⁰⁶Interview with P8, June 06, 2018

²⁰⁷ Interview with C2, June 07, 2018

²⁰⁸Interview with W/ro V3, June 12, 2018

²⁰⁹ibid

²¹⁰ See the next sub-topic on the 'right to education' to have a clear picture of the school.

other students should be there up until 8:00 am, to line up and participate on the national anthem. Once again, while students with ID were dismissed at 11:00 am, others are dismissed at 6:15 am in the morning shift.²¹¹The tendency of the two groups of students to play together or share any other thing is limited according to the directors' view. Students with ID used to confine themselves around their class room and play among themselves even at break time than to play with other students without ID. On the other hand he stated that he did not see any stigmatizing view by the side of other students which clearly hinders students with ID from having relationship with students without ID. From his expression it seems that students without ID are indifferent on having relationship with students with ID or not. Neither the school mini-media nor other clubs of the school had worked on awareness creation about this issue.²¹²

With regard to the relationship between the administrative staff of the school and students with ID, it was all through their teacher, that they tried to communicate. None of the school heads knows sign language though most of the students with ID in their school were also with hearing impairments. Hence, this makes the communication difficult. However, the school seems to overlook this problem believing that the knowledge of the teacher suffices.²¹³ However, the teacher only knows some simple sign language terms, like greetings, some orders and basic goods necessary for teaching purpose. She does not take any course on sign language. Hence, for her it still is difficult to teach these students without knowing sign language which is the only means of communication for most of her students, let alone trying to solve their problems with school administration.²¹⁴

In general, children with ID are in most cases discriminated and segregated from the community. The very first reason for this is the attitude of the whole community towards children with ID. At some point parents' are unwilling to let the children have relationships with the community. And in a situation where the parents make their child with ID free, either people are taking advantage of the child with ID or totally stigmatizing them from participating in any kind of social life. The other reason is lack of interest by the side of the child with ID to have relationships with other children without ID, and vice versa as the case may be. The first one is most of the time related

²¹¹Interview with D1, June 14, 2018

²¹² Ibid

²¹³ Ibid

²¹⁴Interview with T1, on June 14, 2018

with lack of confidence. One way or another the whole problem is related with the attitude of the community.

4.4 The Right to Education

ID is a disability related with mental development i.e. the capacity to understand either what is going on around them or formal education to the level expected in the normal course of things. On the other hand people's mental development is highly influenced by education which is obtained through formal and/or informal means. For the purpose of this thesis we will only focus on formal education to be given at schools.

As it has been stated somewhere in this thesis, the time the data was collected, none of the participant children with ID were enrolled in education. However one child with ID was learning a sign language with deaf students, since she has a multiple cases, i.e. ID and hearing impairment. The girl with ID dropped out of that school because of illness.²¹⁵

On the other hand there was also one special class for children with ID at Awaro Elementary School. The School used to administer that special class in collaboration with VCBRA. However at the time of data collection the school already ceases to give education for those students with ID. The reason for the school to stop teaching students with ID is lack of trained teachers who substitutes, the only teacher graduated in special needs and teaching in that school. The maternity leave of the only teacher of the special class was the reason for the school to stop teaching students with ID. The school claims that there are no other teachers who are trained in special needs and can substitute her.²¹⁶

Though the director said that there is no teacher trained in special needs, there were two teachers who are trained in this field of study as a minor.²¹⁷ Hence it was because of the failure of the school and education bureau that the students are forced to leave the school.²¹⁸ Yet those teachers trained in special needs are there but the problem is lack of interest to teach students with ID. In the existing situations the only teacher of the special class is not even happy by being a teacher of those students. Her reason is first the need to be assisted by other teachers, trained nannies, and

²¹⁵Interview with V1, June 14, 2018

²¹⁶Interview with D1, on June 14, 2018

²¹⁷Interview with T1, on June 14, 2018

²¹⁸ibid

lack of the necessary materials for teaching-learning purpose. Some of the students with ID cannot even use toilet properly and she has to teach them that. But there is no suitable toilet for this purpose. Hence, she has to do all the cleaning staff while her students mess up their clothes and the class room. VCBRA only provides napkins and sanitary pads for girls.



Photo 2: The main gate of Awaro Elementary School and the special class room reserved for students with ID.²¹⁹

The school and VCBRA are getting prepared to commence class in the coming year; hence T1 will be once again the only teacher and nanny of the students with ID.

Coming back to the experiences of the study participants, seven of them reached at the age of education. But none of these children were learning at the time of data collection. However, some of them are drop outs for various reasons. They were first registered in an inclusive class. But, since they cannot cope up with other students without ID they dropped out of school. C8 dropped out of Liben Mecha Elementary School based on her fathers' decision to let her begin school at Awaro School in a special class. But she was also forced to drop out of this school

²¹⁹ The special class was locked for months and all materials used for teaching were destroyed. In most cases they teach the students different types of technical works. But, there was no material that helps to teach any kind of technical works. The room was all empty except those old materials seen on the picture and there is no other place where the materials are stored. The materials were already stolen, and that is why the room is all empty.

since it became practically impossible to walk on foot for four hours per day, for a 10 year's old girl and her father, the bread winner of the entire family. C8s' father cannot pay her transportation fee because of financial problem; hence she was once again forced to leave the school. However, as it has been mentioned under chapter three of this thesis, issues related with financial problems like transportation fee is the duty of the government. Though, C8 claims that she wants to go to school with her half-sister F3, because of the failure of the government it is becoming impossible for her to do that.²²⁰ The government, in principle has to make the school accessible. But, in case this becomes practically difficult for the time being, at least it has to manage the way the children will get to school. The fact that some rights are progressive and are dependent upon the existing resource does not totally relieve the duty of the government to respect, protect and fulfill those rights. The government has to find other means for the enjoyment of the rights using the existing resources, so that all citizens equally enjoy their rights. Hence, providing means of transportation is easy and manageable way out for children who cannot access school in their locality.

On the other hand two of study participants were pushed out of Ambo Elementary School against their will and in a manner that humiliates them. One of teachers' always used derogatory and insulting words against a student with ID. The teacher was saying that the student is dull who understands nothing and hence, better go back home and work on farmlands. Since the teacher used to say all this things in front of other students, the classmates of the student with ID started to make fun of him. Then after, he turned out to be violent and begun to beat other students. Finally, on unexpected situation he was told by the teacher that he is dismissed from the school and he shall never come back to that place again. From that day onwards, he was never been admitted back to that school.²²¹ For the same reason, another student also dropped out of the same school since it was hardly possible to stand the psychological pressure the school environment puts up on her. The student with ID was always told by the teacher that she is stupid, after being asked to answer questions if she doesn't get the correct answer. Parents have a responsibility to advocate for their child's rights when they are not being fulfilled by governments and others as it has been stated under chapter three. Challenging a school's refusal to admit a child with a disability and any kind of mistreatment are instances of this responsibility. However, before that,

²²⁰ C8 can talk a little bit though it is so difficult to understand what she says.

²²¹ Interview with P6, on June 07, 2018

parents should be aware of the rights of their child with ID. This is once again the duty of the government and an area where the government fails once again.

Regarding the essentiality of learning in an inclusive class for children with disability, it seems that the school community, education bureau, social affair of the city and VCBRA agree. However, when it comes to students with ID, all of them preferred a special class. This is also supported by C5 and her brother, C6, who experienced both inclusive and special classes. They tried to justify their arguments based on the capacity of the students with ID to cope up with other students and the type of education delivered for students with ID which is most of the time related with some technical works than regular education. Especially without the existence of necessary materials for learning that supports students with ID to better understand their education, talking about inclusive education is none sense.²²²The researcher is also convinced with this argument after looking at the situation of children with ID in the city and the status of the school delivering education for them. Though inclusive education is the principle, still the Salamanca Statement gives a loophole using a phrase, ‘...unless there are compelling reasons for doing otherwise. Hence, first, the researcher believes that none existence of well-organized school that meets the needs of students with ID can be considered as a compelling reason. In fact accessibility and fulfillments of the necessary materials including means of transportation is the duty of the government as per the provisions of CRPD. But the government failed at this point. Hence, to fill the gap it is better to have special classes for them than to lose education as a whole.

Secondly, the researcher strongly believes that educating children who are victims of severe and profound ID in an inclusive class will have no positive impact on them. As it has been stated under chapter two of this research paper, Severe ID is characterized by aggressive acts, self-injury, non-compliance, self-stimulatory behavior and faces a big difficulty on verbal and physical movements. They cannot properly eat, use toilet, etc. on the other hand children with profound ID has a brain full of liquid, which makes their capacity very low even than that of Severe ID. Hence, the researcher believes that this is another compelling reason to have a special class for them. In the case at hand inclusive education is practically impossible and is with no ultimate positive consequence. Therefore, giving them an education that fits the real situation

²²² Interview with V2, on June 12, 2018

they are living in suffices, than trying to make them sit in an inclusive class talking of complicated concepts which does not give them sense. Here one has to bear in mind that for children with ID which is not severe or profound, preparatory special class is also advisable before inclusion. This may make their life in an inclusive class easier and comfortable since it will give them a chance to know the school environment and how to have relationships with others.

To wind up, the right to education is also one important right of children with ID, which is being highly violated in the city. This is because of the existence of no participant child with ID enrolled in education in the city. There is no school having a special class for them or having a student in an inclusive class knowing the fact that the student is with ID.²²³From this one can possibly draw a conclusion that the attention given to the right to education of children with ID is almost near to zero.

4.5 The Right to Participate in Play, Recreation, and Leisure

Children begin their life lesson and learn how to do things through play. They learn how to decide on life through play. Hence playing is one important tool for them through which they can develop the capability of their brain. Once again it is also a right of children recognized under international and regional documents.

Coming to the findings of this research, the very first time the researcher visited the study participant children without appointment; it was only C8 and C2 who were playing. There is no participant child with ID having a friend other than his family members.

²²³This is because of the probability of having a student with mild ID, who is at the boarder of normality and disability and in most cases not differentiated from students without ID



Photo 3: A child with ID playing with her half-sister.²²⁴

Though there are children with ID who want to play with other children without ID, the latter are not willing to play with them in some instances. Some children without ID do not want to play with children with ID claiming that the latter does not know how to play. Two children shown on the above photo behind the two sisters are younger than the child with ID who is playing. But they do not want to play with her.

On the other case, there are neighbors who prohibit their children from playing with a child with ID. Parents and older brothers and sisters of children at the neighborhood immediately take back their child/younger brother or sister if they see him/her playing with the child with ID. They also warn and order their own children not to play with the child with ID. The neighbors even go to the extent of saying that the brain of the child with ID is with some kind of problem as a result of which he/she might hurt their children. After VCBRA trained the whole family members of the child with ID on this issue, some of them became very eager to see their child playing with other children of his/her age. However, in places where neighbors prohibit their child from having any relationship with children with ID, the latter is mandated to sit alone in front of his/her house and

²²⁴ Such kind of play expects the existence of at least three children. However, since other children think that the child with ID shown above cannot play properly, they were not willing to play with her. That is why the two sisters use the tree instead. The little sister was laughing at her older half-sister saying that ‘she cannot, ..she doesn’t know how to play’ the moment she failed to jump properly as it is shown on the picture. From the facial expression of the child with ID at that moment, one can understand that she was so disappointed.

watch while other children plays. At this time other children used derogatory terms or throw stone on the child with ID looking at them. Hence, the child with ID immediately takes measure upon them by beating them back. The family thinks that the stigma turns out their child with ID to be violent.

The study participants who are under three years are highly dependent upon their family and are not at the age of having friends. Thus, since it is yet so early for those children to start relationship outside their home, they still play or recreate themselves with the help of their family. There is a good relationship between those children with ID and their family. But the real problem starts after this, i.e. the time the children want to have friends outside the family members, to play with.

In general, the data shows the violation of Article 31 of CRC, that requires equal opportunity, appropriate play to the age of the child and finally an inclusive play. There is a clear discrimination against children with ID since the field of play is not equally open for them. They are excluded from the fields and pushed away and forced to be confined on a given space. Thus, this right is also being violated once again.

4.6 The right to best possible health

In the normal course of things it is advisable for all human being to go through annual medical checkup. This is what all individuals are expected to do.²²⁵Especially when it comes to children with such kind of disability the checkup becomes necessity since the disability is followed by different kinds of diseases, like heart, throat and teeth.²²⁶As it has been mentioned somewhere in the preceding chapters of this thesis, ID results to a slow mental and physical development. Hence, following the status of the child through medical treatment is mandatory.

Among the study participants, some of them are economically on a slightly better position. Tomean that, they can afford payment of government hospital in case their child with ID feels sick. In all other cases, all of the informants are dependent up on the aid of VCBRA for medical treatment of their child with ID. As a matter of fact none of the informants took their children to medical centers for annual medical checkup. Parents/guardians only took the child to hospital

²²⁵ Interview with Dr., on June 14, 2018

²²⁶ Ibid

only if the child gets sick. Related to this issue the problem is the money that should be paid to the hospital. VCBRA in principle covers the expenses after the child is taken to the hospital and only when the client comes with a receipt. Hence, if the family does not have money for medical treatment at the moment of illness, the child may not get the treatment. This is what the social workers visiting their clients regularly are facing frequently. If they are informed that the client is sick and the family does not have money, what they usually propose is borrowing from neighbors or relatives, which could be paid back by the association. However, in an extreme situation, where at least eating once per day is hardly possible, the social workers sometimes pay from their own pocket or VCBRA manage the issue as a special case where one of the social workers is assigned to take the child to the hospital for treatment.²²⁷

Regarding health professional and healthcare centers, there is no hospital or clinic specialized on problems related with ID in the city. Ambo hospital has got one room for all kinds of mental illnesses including insanity. In addition to this, except on the medical complications that existed, health professionals did not take any courses on how to treat or approach a child with ID. They do not take trainings on rights of children with ID.²²⁸ The health centers also do not have an interpreter for children with hearing impairments.

Children with ID can walk, talk and do any other thing much later than other children of their age without ID. In all most all cases there is a need to support them through physiotherapy so that they can be able to sit properly, stand and walk.²²⁹ As it has been mentioned above, giving physiotherapy is one of the works of VCBRA social workers. The social workers are trained on this and they train the family how to help the child. The physiotherapy has its own stage and first they work on the neck of the child, so that he/she became able to shoulder his/her head. Then after the therapy helps the child to properly sit, stand and finally walk. The association delivers sitting, standing and walking frames to the child.²³⁰

²²⁷ Interview with V4, on June 12, 2018

²²⁸ Supra note 193

²²⁹ Interview with V3 on June 12, 2018

²³⁰ Ibid, the social workers are expected to visit their clients' twice per week. But the therapy is expected to be conducted per day. Hence on the days the social worker does not visit the client, the families should help the child to go through the therapy. Those families helping their child on therapy shows an amazing change within short period of time. But where families are reluctant and only rely upon the social workers help, the change is very slow.



Photo 4: Children with ID using sitting, standing frames and on physiotherapy

The association extends its aid related with health care to other persons who applied even though they are living outside the local area that the association planned to cover. In such cases, if any person requests their help especially money for medical care services for a child with disability, the association will provide them regardless of their local area.²³¹

In principle the CRPD places an obligation on governments to ensure those children with disabilities can access health services, and also they are provided with the same range, quality and standard of healthcare and health programs as others.²³² Practically no action is being taken to ensure that health facilities and equipment are accessible.

4.7 The Right to an Adequate Standard of Living

It has been stated in this thesis that while poverty is a reason for disability, disability in turn becomes a reason for poverty. This is what this research has proven. There is no big difference related with the living standards of the participant families. As it can be easily seen from annex

²³¹ Interview with V1, on June 12

²³² See article 25/a of CRPD

A half of my informants' earning is irregular. It is dependent upon the parents getting job per day. Hence, let alone having a living standard which is an adequate, whether that family will be able to have food per day is always under question mark. Families whose income is regular are also not living in a much better standard of living. For instance, taking one of the study participant family, their net income from both parents is approximately birr 4,500. This family has the minimum number of members from all other informant families. They are four in number. Assuming that all of the family members expends equal amount of money, if we divide the income for all of them, they will earn birr 37.5 per day. Currently \$1 is changed for 27.78 Ethiopian birr and World Bank put \$1.9 as poverty line.²³³ Hence, using the scale the family is living below poverty line since they earn \$1.34per day.

The participants of the study are living in a slum area where many houses are constructed without plan, with no clear cut boundary for each of the neighbors, and where garbage is thrown here and there. Many of the roads taking to the houses do not even have enough space for ambulance on emergency cases. It is only C5 and C6 who is living in a slightly better place related with the environment since they are living at the periphery of the city.



²³³ The international poverty line is a monetary threshold under which an individual considered to be living in poverty. The World Bank sets the international poverty line at periodic intervals as the cost of living for basic food, clothing, and shelter changes. In 2015 the threshold is updated to \$1.9 per day. (<https://www.investopedia.com/terms/i/international-poverty-line.asp> , accessed on 21st of July, 2018.

Photo 5: The living room of one of the participants²³⁴

To begin it is only parents of C2, and the two neighbors of C8 who said that the disability existed at the time of birth. All other parents and neighbors have some stories to tell. Though they tried to relate it with some kind of evil spirit, some stories hold water. They are big accidents that can easily affect the brain of a child. The accidents include being attacked by a cow as a result of which the child falls on his back and his head hits the ground.²³⁵ Falling of the child in the kitchen where big wood is used as a means of power for cooking. Such and the like stories are the results of poverty of the family. Because of poverty, parents cannot look after of their babies to the level expected of them; and also can not hire a nanny. In such kind of families, once the child started to walk, he/she will be left alone to play outside the house. Because other family members shall work and earn money with which they will be buying food for themselves and dependent family members.

As it has been discussed under chapter three of this thesis, study shows that children with disability face different kind of accidents because of poor handling. This can be understood from the big wound found on the face of the child shown hereunder. As the picture below shows the girl has got a big wound on her chin and neck. She falls on a hot stone in the kitchen the time her mother left her with her younger sisters and brothers.²³⁶

²³⁴ The Bed is a gift from one of their neighbors. The plastic on the top of the bed is used as a blanket. The child with ID was crying, saying ‘Kenni’ in Afaan Oromo, which is meant by ‘give me.’ She was crying for food.

²³⁵ Interview with P7 June 07, 2018

²³⁶ The hot stone is what is called ‘Gulecha’ in Amharic.



Photo 6: A child with ID having a wound on her face

Five weeks later after the interview is conducted, the researcher visited the study participants and found one of them sleeping alone tied up with a rope.(See photo 8 below)The mother of the child, who was washing clothes for her neighbors for money, arrived soon and untied her child. The child had a wound on her head since she once again falls and the edge of a table hits her head.

Access to clean water is also another problem to some of the families.C5, C6, and C3 do not have access to clean water. Whenever they are not able to get water from their neighbors for whatsoever reason, they have to drink river water.

The second correlation between disability and poverty, i.e. disability being a reason for poverty, is also confirmed by this thesis. To state some instances, C3s' mother cannot leave her daughter alone and go to work, if her neighbor, N6 is not around. If C3s' mother left the house to wash clothes or bake injera for her clients, the neighbor will be looking after of C3. C7s' and C1s' mothers quitted work after delivery of a child with ID. For the same reason,F1s', who is only 19, cannot go to school since there is no one who can look after him. C10s' grandmother who was a merchant became a housewife after his mother went to Saudi Arabia. Thus, all this idleness adds and worsens the poverty that already existed in the family.

Therefore, the researcher concludes that the extreme poverty and the existence of a child with the disability who needs the support of the whole family one way or another, affects the life of the

entire family. Most of the family members especially the mother and other person who is very close to the child with ID is highly depressed and seems to live hopeless life.

The government once again is responsible to discharge such duty. As it has been stated under chapter three of this thesis, article 27 of the CRC demands more than the prevention of absolute poverty and requires that children have access to a standard of living which will enable them to thrive and develop fully, and which is consistent with their human dignity. However, in reality the government cannot even alleviate the problem of absolute poverty, let alone the adequate standard of living that would help the child developmental, spiritual, moral and social as well as physical capacity. In addition to this though the CRPD requires that the steps taken by governments to safeguard and promote an adequate standard of living must not discriminate on grounds of disability, all acts of the government that only takes in to account of other children but not children with ID is discriminatory.

4.8 The Right to be protected from all forms of Violence and Abuses

Violence and/or abuses are the main and frequent problems that these children with ID are facing. The violence and/or the abuse in most cases come from family members, neighbors and school community.

Among the informants, P1 honestly stated that there are times that she cried and prays to God to take her soul or that of her child with ID. In the case at hand, all of the children with ID who are able to walk are beaten by their parents or guardians to warn them and sit without disturbance. Children with ID are more violent and disturbing than other children. In addition to this, the children cannot easily accept orders from their parents; and will do again and again what they are ordered not to do. Hence, it is at this point when the parents cannot easily focus on their own job in the house that they beat, insult and uses humiliating words against their child with ID. Related to this, one of the sad stories is the fact that there is a child tied with a rope. The mother of the child with ID tried to justify this saying that it is to her own interest that she is tied. She raised two instances where car accident was about to happen on her child with ID while she was away. No matter what, if the mother leaves the house, the child will be tied, sits alone and the door is

locked from outside. She is always left in a dark room at this time. The researcher also witnessed this situation.



Photo 7: A rope that is used to tie one of the study participants

The social workers of VCBRA know the fact that the child is being tied but they did nothing to change the situation. In principle the social workers seems to agree with the rights of the child. However, when it comes to this case, they have got such a fear that it will create a problem. The social workers believe that the child might be lost, face car accident, might be stolen or something bad would possibly happen unto her. Hence, they do not want to be the reason for a bad thing that would happen on the child. They argue that before working on the living standard of the child and let her live in a safe place, ordering the mother not tie her child will be against the interest of the later.²³⁷

Regarding school bullying, the story of the two participant children with ID is a good instance. (See paragraph 2 of page 62) The words and acts of their classmates in the school were hurting their psychology, as a result of which both of them does not want to learn in an inclusive class today. Especially one of the informants does not even want to have friends from among students without ID. She said that it is enough for her to hang out with her friends in the special class. She was so dismayed by her stay in an inclusive class at Ambo Elementary School, before her

²³⁷ Interview with V3, June 12,2018

disability was discovered. Besides before the whole family was informed of the disability, she was also abused by her family members, especially her mother and father. The father admitted that he was always feeling sad with what his daughter scored in her lesson and insulted and beats her for that. There were times when her mother was using degrading words whenever the child cannot properly perform her duties in the kitchen as per the clear order of the mother. Furthermore there are also times when she forgets to cook food or clean the house. Hence, the time her mother comes back home, the child might either be beaten or insulted. However, after they know of the disability and the care that she needs, the whole family including her younger sisters and brothers started to help her. Now there is no one who gives her a bad look at home.²³⁸

Though the General Comments of the Committee on the Rights of the Child, both on children with disability and protection from violence mandates the government to take legislative measures, train parents and caregivers, and also ensure that schools monitor any kind of school bullying, none has been done by the government yet. The only achievement that the government mentioned is the agreement that it has with VCBRA. No practical and real work has been done yet.²³⁹The officials and workers assigned to work on issues of disability do not know anything about the case.²⁴⁰Two persons are assigned to work on issues of disability in the workers and social affair office of the city. But both of them do not even know what ‘intellectual disability’ is and what differentiates it from insanity. What they know is the fact that persons with some kind of mental problem are categorized under one type of persons with disability, i.e. mental illness. It is just to fill the gap that they are there. What they are in reality doing is reporting the number of persons with disability that the city has based on a survey conducted. Since they do not have work in many cases they support the other division that works on marital case. In the existence of all the above discussed problems related with children with ID, putting a person who knows

²³⁸ Interview with P6, June 07, 2018

²³⁹ Interview with G1, the former team leader of a division called Social Problems Solving Team at Ambo City Employees and Social Affair office. This person was on leave for education at the time of data collection. He is substituted by another man called. The division assigned two persons who work on disability. However though the new appointee referred the researcher to work with these two persons, both of them were not willing to conduct an interview. They preferred to show to the researcher documents that they have on the issue and they only have a single paper that shows the number of persons with mental illness in the city, which does not have any significance to this paper. At least it does not differentiate insanity from intellectual disability, and also does not classify them based on age. Hence, since the current team leader and employees under him are not interested to give the information, the researcher tried to contact the former team leader, G, who was at his post up until September, 2017.

²⁴⁰ It is the time that officials assigned to work on disability know that I will be using her statement for research purpose that she refused to talk. The researcher had conducted an informal chat with them.

nothing about it and a person who says ‘we do not have anything to work’ is a real and tangible evidence of negligence of the government. Apparently though children with ID are living in an extreme poverty and with no formal education, persons assigned at government offices in the name of these children is earning salary without doing anything and leading their own life, and also teaching their own children. This is entirely the failure of the government who is responsible to respect, protect and fulfill the rights of every citizen, including that of the child with ID, without any discrimination based on age, sex, disability, etc.

Conclusion

The principle is inalienability of human rights under any circumstances except in case when the law provides some limitation because of age, capacity or legal issues. By their nature human right are inextricably linked to human beings. They are not granted and cannot be taken away arbitrarily. However, when it comes to children with ID living in Ambo city, human rights are treated as something one can exercise based on the free will of others, especially parents and the community. The government was expected to intervene at this point to protect those children from abuses, discrimination and violence by others. Yet the government has done little on this issue and also on its obligation to respect and fulfill. There is no credible and concrete work that one can mention on the direct works of the government on issues of children with ID.

The fact that human rights are interrelated worsens the situation of children with ID. This is because; the violation of one right or a restriction put by others illegally results to the violation of many other rights of the child with ID. For instance, the violation of the right the right to participate in play, recreation and leisure is directly related with the right to social inclusion. The same is true for many other rights too.

In general, rights to family life, social inclusion, education, participate in play, recreation, and leisure, the best possible health, an adequate standard of living/protection from poverty, and protection from all forms of violence and abuses of a child with ID living in Ambo city is being violated in a way that needs a special focus of all responsible organs, government, family members, the community and various NGOs’ working on this issue. It is a critical case that needs an immediate action.

Chapter Five: Conclusion and Recommendations

This chapter is devoted to summarizing the core findings of the research, presenting a conclusion drawn from it and forwarding a recommendation.

5.1. Conclusion

Intellectual disability is a kind of disability that has something to do with the learning capacity of a person, i.e. intelligence, be it intellectual functioning or adoptive behavior. Children with ID are parts of the whole community who leads an isolated life and whose rights are being violated. Hence, this research is aimed at assessing the practical implementation of the *rights to family life, social inclusion, education, participate in play, recreation, and leisure, the best possible health, an adequate standard of living/protection from poverty, and protection from all forms of violence and abuse* of children with ID living in Ambo city

The research finds that:

- ✓ The laws, policies and programs provide a very conducive environment for the protection and preservation of the rights of children with ID.
- ✓ None of the informants gave their child with ID into institution for lack of institutions. But more than half of them would do so if they get the chance. Within the family, children with ID are treated in a discriminatory way compared to other children living in that house. Hence, institutionalization is the best option in the existing situation.
- ✓ Late diagnosis of the disability and the extreme poverty count a lot for the mistreatment of the child with ID.
- ✓ There is no child with ID from among the informants who is strictly speaking included in the community. Those children with ID are excluded from the whole community and in many cases confined to a given places alone.
- ✓ No child with ID from among the informants is enrolled on education at the time of data collection. There was one special class for them at Awaro Elementary School. But it was all closed since the only teacher was on maternity leave. Neither the school nor the education bureau and social affair office of the city did something to address the problem.

- ✓ No child from among the informants is fully enjoying the right to participate in play, recreation and leisure. When it comes to children with ID, the environment is discriminatory. Parents prefer to confine their child with ID at a specified place; and also neighbors prohibit their children not to play with the child with ID. Furthermore, other children without ID are not willing to play with children with ID and in another case the child with ID do not want to play with a child without ID. Hence, all directions are closed for children with ID to exercise their right to play and recreate themselves.
- ✓ The right to best possible health of children with ID is once again a right not realized yet. VCBRA is doing much at this point. But still the poverty of the family, the failure of the government to meet the minimum requirements, and also the failure of educational bureau to train all health professional on issues of disability and how to treat patients with ID accounts for the violation of the right.
- ✓ It has been reaffirmed by this research that poverty is both a reason and result of disability. The time the data is collected the living standard of all of the informants was below standard where basic things cannot even be accessed easily. This poverty became the reason for some of the children to be with ID; and on the other hand the existence of a child with ID worsens the situation since the parents or guardians can hardly engage in a work that will generate money, leaving behind the child with ID.
- ✓ Violence and abuses are what children with ID living in Ambo city faces in common. People use humiliating and insulting words against them. They are beaten and in an extreme situation tied as an animal; and also forced to be confined in a specified place. The abuse comes from the family members, the community and from school.
- ✓ The attitude of the whole community is the main reason that lies behind the violation of all rights. The mistreatment and discrimination against the child with ID is highly related with the attitude of the community including the families of the child with ID.
- ✓ The government, a body responsible to address all of these problems did nothing tangible. The employees and social affair office of the city cross-refers to the agreement that they have with VCBRA since no other achievement was registered yet on the issues of children with ID.

5.3. Recommendations

The following recommendations are provided for the effective implementation of the selected rights and to address the problems related with those rights:

- ✓ The social affair office of the city, the school mini media and all other responsible organs like VCBRA and other NGOs shall work on awareness creation. The community shall be informed of the causes of this disability and how victims shall be treated in a non-discriminatory and protective manner, in a language that is clear enough for them. Knowledge about this disability and positive attitude towards it will ultimately change the life of children with ID. For instance since it paves the way to early diagnosis of the problem, it will help eliminate or at least reduce to a considerable degree the mistreatment and discrimination done against them and also give the child with ID a confidence as a result of which he/she considers himself/herself as part of the whole community.
- ✓ There shall be institutions where children with ID who lives under an extreme poverty and degrading situations will be taken care of. The researcher believes that NGOs' shall be encouraged and supported by the government to establish institutions.
- ✓ The Ministry of education and the Ambo city Education Bureau shall respect its duties under international and national laws. It shall make schools available, accessible, acceptable and adaptable to children with ID without any discrimination compared to their fellows without ID.
- ✓ Inclusive education shall be the principle. However, the researcher believes that there are two exceptions that necessitate special classes. First, for all children with ID whenever the necessary materials for learning are not fulfilled; and second for children with severe and profound ID, since they can hardly understand a complicated science and compete with other children without ID. But still it is advisable to take a special class for all students with ID before they join an inclusive class to make them ready and easily immerse in an inclusive education. This preparatory special class will have a positive impact on the child with ID since it will give him/her a chance to know the environment of the school and how to approach other people, especially taking in to account that the child is was in most cases confined in a given place alone.

- ✓ The Ministry of Health shall respect its duties related with provisions of adequate health services. It shall make health centers physically accessible and work on the capacity of health professional in treating children with ID. The government shall conduct surveys and construct additional health centers that fit the special needs of children with ID. It shall fulfill the necessary equipments and trained man power on this issue, so that children with ID exercises their rights equally. It shall make sure that services obtained by all other children without ID is also extended to children with ID in the city.
- ✓ The Social Affair Office of the City and parents of the child shall make sure that children with ID are getting play appropriate to their age and capacity. It shall look for other means like constructing parks where children with ID plays for free and above all work on awareness creation so that these children have friends to play with from the neighborhood and schools.
- ✓ All responsible sectors of government offices like shall work to improve the living standards of children with ID and their families. It shall create a comfortable environment for parents/guardians of the child with ID to work. For instance it shall provide a day care services for children with ID, it shall give financial aid and also it shall support the child with ID on issues like sanitation and transportation.
- ✓ The law enforcement institutions of Oromia region shall protect the children with ID from abuses, violence and undue discrimination. It shall also work on awareness creation to protect children with ID from abuses. To this end, it shall also formulate laws and execute them strictly on perpetrators of the undue discrimination and abuse. Discrimination is more often experienced by children with ID because of the acts and abstention of the government itself. Hence, the government shall also react and refrain at another time from engaging on works that discriminates children with ID. This includes, giving a higher attention to majority of children who are without ID and who needs a much lesser effort and be negligent of the interests of children with ID claiming that it is dependent upon the available resource. The other is not taking any measures on perpetrators of abuses. Thus, the government shall refrain from such kind of discriminatory acts.

- ✓ The Social Affair Office of the city shall promote public awareness of positive, nonviolent forms of parenting; and train and educate parents or others caring for the child to understand the risks and detect the signs of abuse of the child.

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Interview with the child with ID (C)

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Interview with C6, a child with ID, at his own house on June 07, 2018
Interview with C8, a child with ID, at her house on June 06, 2018

Interview with Neighbors of the child with ID (N)

Interview with N1, C5 AND C6s' neighbor, children with ID, at his house on June 07, 2018
Interview with N2, C1s' neighbor, a child with ID, at C1s' house on June 06, 2018
Interview with N3, C4s' neighbor, at her own house on June 06, 2018.
Interview with N4 C8s' neighbor, a child with ID, at her own house on June 11, 2018
Interview with N5, C2s' neighbor, a child with ID, at C2s' house, June 06, 2018.
Interview with N6 C3s' neighbor, a child with ID, at her own house on June 11, 2018

Interview with other family members of the child with ID (F)

Interview with F1, C9s' aunt and a person taking care of him, a child with ID, at her own house on June 08, 2018

Interview with F2, C10s' aunt, a child with ID, at her own house on June 07, 2018

Interview with F3, half-sister of C8, at her own house, on June 06, 2018

Interview with VCBRA workers (V)

Interview with V1, a supervisor at Vision Community Based Rehabilitation Association, at her office on April 04, 2018

Interview with V2, the administrative and finance head of Vision Community Based Rehabilitation Association, at his office on June 12, 2018

Interview with V3, a social worker at Vision Community Based Rehabilitation Association, at her office on June 12, 2018

Interview with V4, a supervisor at Vision Community Based Rehabilitation Association, at her office on June 12, 2018

Interview with others

Interview with D1, the director of Awaro Elementary School, at his office on June 14, 2018

Interview with Dr., a medical doctor at Ambo referral Hospital, at the hospital on June 14, 2018

Interview with G1, former team leader of a division called Social Problems Solving Team office at Ambo city workers and social affair office, at his office on June 13, 2018

Interview with T1, a teacher of students with ID at Awaro Elementary School, at the school on June 14, 2018